HIV / AIDS PATIENTS AND THEIR REHABILITATION: A CASE STUDY OF DELHI

ABSTRACT

THESIS

SUBMITTED FOR THE AWARD OF THE DEGREE OF

Doctor of Philosophy

IN

SOCIOLOGY

By

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Abstract

HIV / AIDS has emerged as most formidable public health problem. It is an important cause of death across the world and it is estimated that every minute one in every five youth (15 – 24 years) is infected with HIV. India is among the most affected nations in terms of HIV / AIDS. Since this epidemic mostly affects the youth in their productive and reproductive years, it poses a serious challenge to economic production and growth in developing countries like India. This makes it imperative that an effective policy is formulated for controlling the epidemic. There is need to identify such factors that could prevent the effective implementation of such a policy. It has been found that stigma and dissemination against the HIV / AIDS patients in the family, community, work place and health sectors. Prevent them from the effective implementation of the policy for controlling the disease. Thus, proper measures for the rehabilitation of HIV / AIDS patients are necessary because this is one crucial factor which prevent the detection and control of HIV / AIDS.

AIDS an acronym for "Acquired Immunodeficiency Syndrome" is the life threatening disease. It represents the late clinical stage of infection with a virus called HIV (Human Immunodeficiency virus). A person infected with virus is called HIV positive and he may look healthy but can at this point infect others if his body fluids (most commonly sperm, vaginal fluids. breast milk) are transferred to another person. After this initial stage of HIV infection there is period varying between eight months and a decade (more shorter for children) when there is no symptom of nay illness until the on set of full blown AIDS.

Since AIDS has no specific symptoms of its own until very lat in the disease but only decreases the persons immunity the person had no clue that he has contracted the infection until "opportunistic infection"

start occurring. Full blown AIDS is marked by major symptoms like weight lose (over 10 percent) chronic diarrhea (persisting over one month) and a few minor symptoms like persistent cough in the absence of known causes of immune suppression or other recognized etiology. Thus, AIDS is the name given to this late stage of HIV infection in which there is evidence of significant impairment to the immune system. The term HIV / AIDS frequently used because the illness is best understood as a continuum from initial infection to the opportunistic infection.

While there is no cure for HIV / AIDS the only therapy shown conclusively to stern the progress of AIDS is called ART. Art consist of three antiretroviral drugs mixed together to prevent drug resistance that bring down the viral load, boosts the immune system and delays further damage to it, and hold out of real possibility of improving the quality of life and longevity of those already infected. Since the disease is itself incurable, ART is a life long treatment. Essentially, it enables the patients to manage the disease just as any other incurable and chronic degenerative disease such as diabetes or Alzheimer's disease.

The cause of AIDS is HIV virus, which is not transmitted through the air, casual contact, by insects, by food and water. HIV lives in high concentration in certain body fluids. If these fluids in an infected person come into contact with the blood of another person, this person is at risk of becoming infected with HIV. In India, the mode of transmission is mostly through heterosexual relationship (85.76%) and only minority infected by prenatal route (3.58%), blood transfusion (2.03%) and by syringe (2.55%). The consequences of HIV / AIDS are not visible in India. The cumulative effects will be visible in India only after one or two decades. The slow evolution of the impact of HIV / AIDS makes it worse than other epidemics. Though the long term consequences of HIV / AIDS are only just being recognized in developing countries like India. It is clear that it will have multiplies effect that not only for families and

communities but also for the demography and economy of these countries.

The mode of transmission and the consequences of HIV is such that AIDS and such that it has spread quickly and it is likely to become a serious challenge to public health in all countries.

In 1982 public health officials in the United States began to use the term "Acquired Immunodeficiency Syndrome" or AIDS to describe the occurrence of opportunistic infections. Formal tracking (surveillance) of AIDS case began that year in the United States. The spread of HIV / AIDS is such that an estimated 38.6 million (33.4 m – 46.0 million) people world wide were living with HIV in 2005 and an estimated 2.8 million (2.4 million – 3.3 million) lost their lives to AIDS. In India the first serologically confirmed HIV infection was detected in 10 of 102 FSWS tested in Madras in February 1986 and first AIDS case was reported in May 1986 – about years after AIDS became clinically evident in USA and Europe. India is the second most populace country in the world but now is going to become second AIDS capital of the world. While the number of HIV infected people in India was just 0.2 million in 1990 but the figure has risen to 5.2 million in 2005. Similarly, the number of AIDS cases in country has risen from 102 (in December 1992) to 103857 (in March 2005). In Delhi the first AIDS case was reported in year 1988 and the number of AIDS cases has risen from 45 in 1993 to 2592 in January 2006.

The present study deals with the problems of rehabilitation of people living with HIV / AIDS (PLWHA) in Delhi. Delhi has been selected universe of study because as the capital of India, it occupies a prominent place as the industrial and commercial hub of North India. The presence of migrants CS workers, street children, intra venous drug users, truck drivers and transport worker and refugees, many of whom are poor

and illiterate, makes Delhi highly vulnerable to HIV / AIDS. The problems of rehabilitation of HIV / AIDS patients has hitherto remain unexplored and so there is need for exploratory research design.

Sellitiz, Jahoda and Cook have suggested the procedure of exploratory research as consisting of the following three stages.

1. **The Survey of Literature:** In this study this includes designing rehabilitation in the context of HIV / AIDS patients and explaining the dimensions of rehabilitation.

2. **The Experience survey:** In this study such experience person in the area like counselors, directors of NGO's and social workers and concerned government officers who are likely to give insights into the problem under investigation are key informant. The knowledge and experience of the key informant was collected through conversation with them on the area of their specialization.

3. **The analysis of insight stimulating examples:** This was followed by the intensive study of selected case of individual using semi structure, in-depth interviews, schedules and participant observation to describe the experiences of PLWHA in order to capture the problems of rehabilitation within the family, friend circle, community, work place and in the health sectors.

There are three community care centers run by NGO's which are attached with Delhi government in which there were hundred and fifty beds of which 90 were occupied by HIV / AIDS patients. 25 cases were selected from these care centers for the purpose of conducting case studies with the help of key informant.

Objective of the study:

Objective of the study were as follows.

1. To study the pattern of spread of HIV / AIDS in Delhi.

2. To study government policies for rehabilitation of HIV / AIDS patients in Delhi.

3. To examine the problem of HIV / AIDS patients in getting care and treatment at hospitals in Delhi.

4. To examine the role of NGO's and its services for rehabilitation of HIV / AIDS patients in Delhi.

5. To examine the discrimination of HIV / AIDS patients in Delhi in their families, friend circle, community and coworkers at work place.

To suggest guidelines and policy implication for an action strategy for the effective rehabilitation of HIV / AIDS patients.

The present study deals with the problem of the rehabilitation of HIV / AIDS patients in Delhi. While prevention of HIV / AIDS remain a high priority, there is great challenge in comforting the need for rehabilitation of people living with HIV / AIDS. The rehabilitation of HIV / AIDS patients has two dimensions.

1. Provision of care, treatment and support which is largely a medical dimensions. Since care and treatment needs are expanding rapidly, the current treatment facilities can provide service to only small percentage of HIV / AIDS patients. Therefore, it is necessary to make provision of comprehensive HIV / AIDS care and treatment which integrates the existing health infrastructure consisting of

care center run by NGOs, drop – in – center, public health facilities, private clinic and network of PLWAH. This system of care and treatment must be link to support system through counseling and testing centers. These counseling and testing center will provide a supportive environment for HIV / AIDS patients so that they remain in the main stream.

2. Adjustment within the family, community and work place, which is a social dimension. It goes without saying that HIV / AIDS is as much a social concern as a medical concern because the disease is also associated with stigma and discrimination against HIV / AIDS patients. They face discrimination in family, community, work place and health sectors when they need support the most.

Few important observation emerge from the case studies when the treatment is sought from a government hospital the patient incur substantial expenditure, though less than the amount spend while seeking treatment from a private doctor. Almost all the HIV / AIDS patients first consulted a private doctor for treatment of these infection and spend a considerable amount of money on the treatment which in some cases led to the selling of their asset such as house or shop, mortgaging of land, selling of ornaments and borrowing of money from relatives or friend. In private clinic they have to spend money on every thing including doctors fee, bed charges, medicine, diet, blood test and blood transfusion. In a government hospital money is spent on transport, costly medicine are not available in the hospital. Blood test for CD4 count and tips to hospital staff for getting care and treatment. Even though the expense in the government hospital were less, the cases reported that there is stigma and discrimination one reason for this is that in most cases they enter in the government hospital after confirmation of HIV positive status and the result of the test is not kept confidential as under rules. The other reason

is that a private doctor always refers patients who are suspected to be HIV positive to government hospital and are not under any obligation to treat them as doctors in government hospitals. The discrimination in the government hospital takes many forms such as denial of bed facilities or early discharge on the pretext of over crowding, facing isolation in the ward with separate arrangement of bed in gallery or corridor, refusal to touch the patients for taking blood pressure or temperature, scolding and shouting at the patients to keep them at a distance, restricting their movement around the ward and neglecting them and not attending to their needs.

It is because of this stigma and discrimination faced by HIV / AIDS patients and the money spend in government hospital that they go to community care centers run by NGOs. They go there on the advice of their friends or relatives or volunteers of NGOs who also tell them that they will spend much less in such centers than government hospitals. These care canters provide free diet, free medicine and rent free accommodation. They also get free regular check up but they have to pay Rs. 1200 for CD4 count, which is necessary for proper medication of patients. All the cases of HIV / AIDS patients reported that there is no stigma and discrimination against them in these care centers and they are treated as family members. The staff of the care center is very cooperative, sympathetic and supportive and includes a few HIV positive persons who are employees of the care center. These care center especially cater to the needs for care and treatment of only HIV / AIDS patients.

The initial reaction of the spouse and family members of these case of HIV / AIDS patients who revealed their status was of shock, embracement, anger, misunderstanding and disbelief. Later on in most case studies the attitude of spouse and family members of HIV / AIDS patients changed and they give care, support and sympathy. There are few

cases of HIV / AIDS patients faces physical isolation at home form family members and relatives such as separation of sleeping arrangements and utensils. This discrimination may be because families with infected members find that expenditure increases, as the person requires medical and special diets. AIDS places new often unaffordable demand on resources and time, which quickly result in depletion of family income caring capacity of family saving and assets. In addition, the social stigma and discrimination against these families by the community further exacerbates their economic hardship and accounts for the discrimination against infected members. There were also few cases of HIV / AIDS patients who have not disclosed their status to their families and the reason they give is the fear of being rejected, neglected, insulted or scolded by family members.

It has been seen that more women are being discriminated against as compare to men. Wives and daughter-in-laws experience higher level of discrimination than son. This shows that women bear the brunt of HIV infection and they are the most adversary affected psychologically and socially. They do not get much cooperation for getting treatment and care when they have to get treatment, no one accompanies them. One thing that comes out in most of the case studies is that the daughters-in-law are treated much worse than the sons and there is no space in the family and share in family property for them, if the son dies. These widows get shelter in their parent's home if their parents are alive and have control over the family affairs. The parents are actively involved in care giving and in providing financial and material support for widows with HIV and in most cases they also bear the burden of bringing up their grandchildren.

The reaction of friend / community to those cases of HIV / AIDS patients who revealed their status is mostly of stigma and discrimination such as refusal to shake-hands, avoiding setting hear them, not having tea or food with them teasing and ridiculing them. Negative community

reactions towards (PLWHA) arises also from questionable character of the PLWHA apart from their HIV status. It is this fear of ostracism, isolation, social boycott and rejection which prevent HIV / AIDS patients from disclosing their status to friend / community they feel that revealing their status would adversely affect the reputation of family and the marriage and job prospects of its other family members. The negative reaction of the community is not only against HIV / AIDS patients but also their families. Till the death of their parents and those who take care of HIV / AIDS patients. The family members feel avoidance and rejection by neighbors and the staff who care for HIV / AIDS patients are also regarded with distrust and suspicion.

In the work place stigma and discrimination against cases of HIV / AIDS patients operates in form of forcible resignation or retirement or going on long leave or forcing dismissal. It is because of negative attitude that HIV / AIDS patients in most cases do not reveal their status at the work place.

Stigma and discrimination against HIV / AIDS patients is not there only in their lifetime but also continue even after their death. The death of the HIV / AIDS patients creates many problems for the care center or hospital staff, in some cases there is no family member to take care of dead body. Even when there is family member, in most cases they do not want to take it back home for cremation because the stigma attached with disease will adversely affects the rejection of the family. So they want to cremate the body in Delhi itself and they leave it for the care center or hospital staff. The government gives only Rs. 500/- for cremation of the dead body of HIV / AIDS patients and this amount is not sufficient even for transporting the body to the cremation ground. Stigma and discrimination take such form as refusal to lift the body after death not giving transported facilities as well as the facilities to keep the dead body

in a mortuary, denial of the use of common cremation ground and performance of last rites.

The rehabilitation of HIV / AIDS patients is very important because the stigma of discrimination against HIV / AIDS patients will endangers non - HIV / AIDS person. It will send a clear signal to HIV / AIDS patients whose behaviour put them at risk of HIV infection to hide or otherwise avoid being identified. The way in which the non - HIV / AIDS persons react to HIV / AIDS patients will make the difference between success and failure of HIV / AIDS prevention. Protecting the rights of people without HIV is best served through the protection of the people who have HIV / AIDS has been decided as the biggest ever-human right challenge for the international community. PLWHA have right to be free from discrimination, the right to information, employment, confidentiality and privacy, sexual autonomy, the right to accessible and affordable medicines, the right to life and health. All these rights over under threat in various ways in relation to HIV / AIDS.

The international labour organization (ILO) and World Health Organization (WHO) developed recommendation to protect the right of PLWHA in the work place. The international guide lines from UNAIDS in 1998 highlights the 12 areas of HIV related discrimination and made recommendations to assist states in translating international human rights norms into practical observation in the contexts of HIV / AIDS.

On the basis of the result of the study it is possible to suggest guide line and policy implication that take the form of action strategy for rehabilitation of HIV / AIDS patients.

1. The study shows that most of the HIV / AIDS cases were in the prime of their youth which is highly productive and reproductive age group and this fact made a imperative that there should be a proper rehabilitation. The government and

NGOs must emphasize proper care, treatment and support of HIV / AIDS patients as well as there social adjustment by removal of the stigma and discrimination against them in the health sectors, families, friend circle, community and work place.

2. Legislation must be pass to ensure the rights of HIV / AIDS patients to education, employment, social security and to health.

3. ART which is very costly must be made available to HIV / AIDS patients at a highly subsidized rates, if not free of cost.

4. The facilities of testing and counseling must be extended and strengthen because it is necessary for the rehabilitation of HIV / AIDS patients. In particular, the facility for HIV and CD4 count test must be provided free of cost in community care centers run by NGOs.

5. The HIV / AIDS patients need financial assistance and jobs and the government and NGOs should ensure this is order to provide economic security, proper treatment and diet.

6. Organizations and network of HIV / AIDS patients must be encourage so that they can give voice to their grievance ad increase their social adjustment. It will serve as support system in order to campaign against stigma and discrimination in the family, friend circle, community, work place and health sectors. This empowerment will also enable them to fight for their right to education, social security, health and employment.

7. It is work of media and NGOs to spread the awareness about nature and causes of the disease. The only way to remove discrimination is to clear the misconception about the disease such as that it spread through breathing, smoking, shaking hand, sitting near by, using same utensils, sharing same toilet seats etc. The awareness campaign of the government is reaching only the educated people in urban areas. Since HIV / AIDS affects more illiterate people in slums and rural areas, it is necessary to spread the message to these sections.

8. The government is not providing adequate funding for care, treatment and support for HIV / AIDS patients. These funds are inadequate because the government does not have proper statistics about the number of HIV / AIDS patients. There is huge gap in India in terms of research on HIV / AIDS what is needed is high quality research to give precise data on the extent of HIV / AIDS in the country.

9. The NGOs have an important and very special role in spreading awareness about HIV / AIDS intervention necessary for prevent, care, treatment and support of HIV / AIDS patients. NGOs are not under some constraints as government programmes and so they have greater flexibility and the capacity to accommodate change programme according to public needs and implements new initiative easily.

This study is broadly concerned with the use of exploratory research design to examine the problems of rehabilitation of HIV / AIDS patients in Delhi and to suggest guidelines and policy implication for an action strategy for the effective rehabilitation of HIV / AIDS patients.

Exploratory research design was followed because the area was hitherto un-explored. This research enabled us to gain familiarity with the new phenomenon and to give new insight. Further, in-depth research needed in this area by formulating precise hypothesis and appropriate research design for their verification.

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Dated.....

Certificates

This is to certify that **Mr. Shekh Belal Ahmad** has worked under my supervision of his Ph.D. thesis entitles *HIV / AIDS patients and their rehabilitation: A case study of Delhi.*

To the best of my knowledge this work is of original nature and suitable for the award of Ph.D. degree in sociology. He has also completed all the requirements for the submission of the Ph.D. thesis at the Aligarh Muslim University, Aligarh.

(Dr. P.K. Mathur)

Reader

Supervisor

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As a special gesture of appreciations I would like to thanks my parents and friends.

Shekh Bejal Ahmad

List of Acronyms

AIDS	:	Acquired Deficiency Syndrome
ART	:	Antiretroviral Therapy
CD_4	:	A quantitative Laboratory maker of Immune Function
CSW	:	Commercial Sex Worker
GDP	:	Gross Domestic Product
HIV	:	Human Immunodeficiency Virus
ICE	:	Information Education Communication
ILO	:	International Labour Organization
NACO	:	National AIDS Control Organization
NGO	:	Non Governmental Organization
OI	:	Opportunity Infection
PLWHA	:	People Living With HIV / AIDS
STD	:	Sexually Transmitted Disease
TB	:	Tuberculosis Bacillus
UNAIDS	:	United Nations Programme on HIV / AIDS
UNESCO	:	United Nations Educational Scientific & Cultural Organization
UNICEF	:	United Nations Children's Fund
VCTC	:	Voluntary Testing and Counseling Center
WHO	:	World Health Organization

CHAPTER – 1

Introduction

HIV / AIDS has emerged as most formidable public health problem. It is an important cause of death across the world and it is estimated that every minute one in every five youth (15 – 24 years) is infected with HIV. India is among the most affected nations in terms of HIV / AIDS. Since this epidemic mostly affects the youth in their productive and reproductive years, it poses a serious challenge to economic production and growth in developing countries like India. This makes it imperative that an effective policy is formulated for controlling the epidemic. There is need to identify such factors that could prevent the effective implementation of such a policy. It has been found that stigma and dissemination against the HIV / AIDS patients in the family, community, work place and health sectors. Prevent them from the effective implementation of the policy for controlling the disease. Thus, proper measures for the rehabilitation of HIV / AIDS patients are necessary because this is one crucial factor which prevent the detection and control of HIV / AIDS.

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Since AIDS has no specific symptoms of its own until very lat in the disease but only decreases the persons immunity the person had no clue that he has contracted the infection until "opportunistic infection" start occurring. Full blown AIDS is marked by major symptoms like weight lose (over 10 percent) chronic diarrhea (persisting over one

month) and a few minor symptoms like persistent cough in the absence of known causes of immune suppression or other recognized etiology. Thus, AIDS is the name given to this late stage of HIV infection in which there is evidence of significant impairment to the immune system. The term HIV / AIDS frequently used because the illness is best understood as a continuum from initial infection to the opportunistic infection.

While there is no cure for HIV / AIDS the only therapy shown conclusively to stern the progress of AIDS is called ART. Art consist of three antiretroviral drugs mixed together to prevent drug resistance that bring down the viral load, boosts the immune system and delays further damage to it, and hold out of real possibility of improving the quality of life and longevity of those already infected. Since the disease is itself incurable, ART is a life long treatment. Essentially, it enables the patients to manage the disease just as any other incurable and chronic degenerative disease such as diabetes or Alzheimer's disease.

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4. To examine the role of NGO's and its services for rehabilitation of HIV / AIDS patients in Delhi.

5. To examine the discrimination of HIV / AIDS patients in Delhi in their families, friend circle, community and coworkers at work place.

6. To suggest guidelines and policy implication for an action strategy for the effective rehabilitation of HIV / AIDS patients.

The second chapter deals with the meaning, causes and consequences of HIV / AIDS. The third chapter is about the origin of HIV and the emergence and spread of HIV / AIDS in the world, in India and in Delhi. The fourth chapter gives the reason for the selection of Delhi as the universe of the study and the research design used in the study. The fifth chapter defines rehabilitation and gives the dimension and its importance. The sixth chapter contains the case studies based on the interviews with 4 key informants. The seventh chapter contains case studies base on interview with 25 cases of HIV / AIDS patients. The eights chapter is an analysis and interpretation of the fourth case studies of key informant and 25 case studies of HIV / AIDS patients. The concluding chapter gives the summary of the problems of rehabilitation of HIV / AIDS patients and guidelines and policy implications for an action strategy for the rehabilitation of HIV / AIDS patients.

CHAPTER – 2

Meaning, Causes and Consequences of HIV / AIDS

HIV / AIDS has emerged as most formidable public health problem. It is an important cause of death across the world and it is estimated that every minute one in every five youth (15 – 24 year) is infected with HIV. India is among the most affected nations in terms of HIV / AIDS. Since this epidemic mostly affects the youth in their productive and reproductive year, it poses a serious challenge to economic production and growth in developing countries like India. This makes it imperative that an effective policy is formulated for counseling the epidemic. There is need to identify such factors that could prevent the effective implementation of such a policy. It has been found that stigma and discrimination against the patients in the family, friend circle, community, work place and health sectors prevent them from disclosing their HIV / AIDS status which is necessary for the effective implementation of the policy for controlling the disease. Thus proper measures for the rehabilitation of HIV / AIDS patients are necessary because this is one crucial factor which prevents the detection and control of HIV / AIDS.

AIDS - An acronym for "Acquired Immune Deficiency Syndrome" is life threatening disease. It represents the late clinical stage of infection with a virus called HIV (Human Immunodeficiency Virus). HIV is a virus, which infects certain cells through out the body. Most significantly it infects white blood cells of the immune system (particularly T – cells) or known as T_4 lymphocytes that serve as its

protective immunity system against infecting germs (bacteria, parasites and viruses). The role of these cells is to help clear disease causing substances from the body (Nag, 1996: 1). A person infected this virus is called HIV positive and he may look healthy but can at this point infect others if his body fluids (most commonly sperms, vaginal fluids, breast milk) are transferred to another person (USDIN, 2005: 68-69). The common symptoms of HIV infection within 2 – 3 weeks of exposure are low fever, fatigue and mild, ted rash on the face. These usually pass unnoticed both by patients and physicians, but within a month or two body produces antibodies (Nag, 1996: 2), which is the immediate response of the body any invasion by an infectious agent that a blood test called (ELISA or west blot) can detect. Since the antibodies first appear in the blood only I six weeks and six months after the entry of the virus (an average of three months), any test that is conducted during this "window period" will not show the reliable results (Ramasubban et al., 2005: 5).

After this initial stage of HIV infection there is period varying between eight months and a decade (more shorter for children) when there is no symptom of any illness until the on set of full-blown AIDS. Since AIDS has no specific symptoms of its own until very lat in the disease but only decreases the persons immunity the person had no clue that he has contracted the infection until "opportunistic infection" start occurring (Ramasubban et al., 2005: 4). AIDS - is a syndrome because it

is not one particular isolated disease but shows variety of symptoms related different disorders and disease. Full blown AIDS is marked by major symptoms like weight loss (over 10 percent) chronic diarrhea (persisting over one month) and a few minor symptoms like persistent cough in the absence of known causes of immune suppression or other recognized etiology. Thus, AIDS is the name given to this late stage of HIV infection in which there is evidence of significant impairment to the immune system. The term HIV / AIDS frequently used because the illness is best understood as a continuum from initial infection to the opportunistic infection.

The CD4 test is ordered when a person is first diagnosed with HIV as a part of base line measurement test are repeated every six months. The CD4 count in healthy adults ranges from 500 to 1500 cells per cubic millimeter of blood. In HIV infected people, it goes down by 60 cells per cubic millimeter of blood per year as HIV progresses. Full blown AIDS is set to occur when the CD4 count is under 200 is administered (Usdin, 2005: 69). The opportunistic infections (OI's) result in more rapid decline in CD4, T-cells. Hence providing treatment for the opportunistic infections is essential for allowing PLWHA to lead an active life. There is five-time lower frequency of opportunistic infections in people on medication.

While there is no cure for HIV / AIDS, the only therapy shown conclusively to stem the progress of AIDS of is a combination of at least

three drugs called ART. The person is a different candidate for beginning combination of Anti Retroviral Therapy (ART). ART consist of three anti retroviral drugs mixed together to prevent drug resistance that bring down the viral load, boosts the immune system and delays further damage to it, and holds out of real possibility of improving the quality of life and longevity of those already infected. Since disease itself is incurable, ART is a life long treatment. Essentially, it enables the patient to manage the disease just as any other incurable and chronic degenerative disease such as diabetes or Alzheimer's disease (Ramasubban et al., 2005: 6).

People on ART must be monitored for side – effects and switched if necessary to alternative combinations of drugs. Drug resistance is a problem, but again people can change to different set of drugs, although eventually they may run out of alternatives. For most people these drugs correctly, this only occurs after many years and by the time, new medications are likely to become available (Usdain, 2005: 133 – 137).

Causes of HIV / AIDS

The cause of AIDS in HIV virus, which is not transmitted through the air, casual contact, by insect, by food and water. HIV lives in high concentrations in certain body fluids such as sperm, blood, vaginal secretions and breast milk. If these fluids in infected persons come into

contact with the blood of another person, this person is at risk of becoming infected with HIV. The modes of transmission is:

1. By sexual transmission, natural and un-natural from one person to another of same sex or either sex.

2. By transfusion of contaminated blood or blood products.

3. By sharing or reusing contaminated needles or razors and tooth brush.

4. During pregnancy, child birth and possible breast feeding from women to child (Jaiswal, 1992: 17).

There are some vulnerable groups which are considered having a high risk of HIV / AIDS infection and there are C.S.Ws. men who have sex with men, intravenous drugs users, migrant, transport workers, children and women. Such groups with high risk behaviour where in the beginning confine to the urban areas but the epidemic is now spread from such high risk groups to the general population. In India the spread of the disease is driven by such social factors as poverty, illiteracy, unemployment and relative powerlessness of women vis-à-vis men, poverty and unemployment result in the need to earn a living by commercial sex work or to migrate to another place in research of work. Illiteracy results in the lack of awareness of the causes for the spread of HIV / AIDS and so to the risk of infection. Relative powerlessness of

women vis-à-vis men results in ability of women to persuade their male partners about the need for safe sex with the use of a condom.

Consequence of HIV / AIDS

In India the consequences of HIV / AIDS are not visible. The studies in Africa indicate that the impact is visible only two decades after the on set of the epidemic in a country. This shows the immediate effect is not visible but cumulative effect is visible only after one or two decades. The slow evaluation of the impact of HIV / AIDS makes it worse than other epidemics. Though the long term consequences of HIV / AIDS are only just being recognized in developing countries like India. It is clear that it will have a multiplier effect that will have profound consequences not only for families and communities but also for the demography, economy and children of developing countries like India (www.unicef.org/2000).

The demographic consequences of HIV / AIDS

The demographic consequences are as follows (UNICEF, 2000).

1. AIDS will not stop population growth but the rat may slow down which could result over – time in smaller population.

2. Age structure of the population may alter due to increased mortality in the 20 – 40 years age group.

3. Sex ratios may shift in some age groups because of higher infection rates and mortality in women.

4. It will sharply reduce the life expectancy in some countries.

5. It will account for a greatly increased some of total death from infections diseases in developing countries. It has already risen to be among the top four killer diseases worldwide – second among infectious diseases. It 1990 it accounted for 2.0% of all infectious diseases deaths, in 2020 it is estimated account for 13.6 percent. Several studies suggest that adults with AIDS use more health care prior to death than those who die of other causes. In severely affected countries HIV infected make up large percentage of patients in the hospital.

6. Projection indicate that in 2010 AIDS may increase the infant morality rate by 75% and under five mortality rate by 100% in worst affected regions.

7. Most women will complete their child bearing before falling ill so the number of orphans will rise.

The economic consequence of HIV / AIDS

The economic consequences of HIV / AIDS are as follows (UNICEF, 2000).

1. It is clear that developing countries will have increasingly great difficulty in finding to resources to meet the need for health care and social support for AIDS patients. AIDS would consume half of national budget for health in some countries if the number of cases and the costs involved just in treating opportunistic infections were taken into consideration. The world bank estimate that if India maintains its current level of health care expenditure, a severe AIDS epidemic would increase government health expenditure by about $ 2 billion per year by 2010. If subsidies are increased by 50% level, the same size epidemic would increase annual government health by an additional $ 30 billion expenditure. The recent study on the economic consequences of HIV / AIDS in India shows that AIDS imposes a major burden on the economic front especially when costs of treatment of people living with AIDS prevention programme and labour costs are also taken into account.

2. It will reverse hard-won gains in development as the increased mortality in the 20 – 40 years age group will reduce the working population, which contribute to the nation 25 growth and economic development.

3. Conservative World Bank estimates suggest that over all growth in GDP per person is barely affected while a country is over all infection rate remains between 5 percent. However, once the disease reaches 8% of the adult population, per capita growth is 0.4% lower and if rate of infection exceeds 25% then per capita growth is at least one percentage point lower than it would have been otherwise. In any given country one year of basic medical treatment for one person cost about 2 – 3 times the national GDP per person.

4. Study on AIDS and industry showed that AIDS would have direct effect on productivity increasing absenteeism leave and medical care.

Consequences of HIV / AIDS on children

Consequences of HIV / AIDS on children are as follows (UNICEF, 2000).

1. Increase in the number of children who loose one or either parents, illness or death of parents or guardians robs a child of emotional and physical support and this is likely to be worse in poor households. Before AIDS, one in 50 children in poor countries was an orphan; in some countries today, the rate is one in 10.

2. Very young orphans whose mothers are infected or die of AIDS have a higher mortality rate than other orphans because roughly one-third of them are themselves infected at or around the time of birth.

3. The stigma and discrimination against HIV / AIDS patients leaves affected children completely isolated.

4. Orphans especially disadvantaged in terms of school enrolment due to reduced ability of families to pay fees, withdrawn from school to earn, help in family chores or care for ailing family members.

5. Child malnutrition is one of the most severe and lasting consequences of death of the adult earner through reduced family

income resulting in reduced food expenditure and consequently a drop in food consumption.

CHAPTER – 3

Emergence, Spread and Control of HIV / AIDS

The origin and spread of HIV / AIDS in the world

While the exact origin of HIV is not known, it is generally accepted that the virus across the world from a species of monkeys in Africa kin the early 1900s. HIV – 1 one of the two major strain of HIV is thought to have spread from Chimpanzees to human in Central Africa. In West Africa the les aggressive HIV – 2 strain is believed to have spread from Mucaque monkey. The spread of virus across species is not a rare phenomenon. It happens with various strains of flue where viruses are passed on through an animal host or reservoir to humans. The conclusion that this is the origin of AIDS is based on similarities between the human and monkey forms of the virus as well as the common geography shared by both the monkeys and human viral strains.

Scientists have different theories about the emergence of HIV in human but none has been proved. The earliest known case of HIV was from a blood sample collected in 1959 from one man in Kinshasha, Democratic Republic of Congo. The genetic analysis of this blood sample suggested that HIV – 1 may have stemmed from the single virus in the late 1940s or early 1950s. It is known if the virus has existed in the United States since at least the mid to late 1970s. From 1979 – 1981, rare types of phenomenon were being reported by doctors in Los Angles and New York among a number of gay patients. These were conditions not usually found in people with healthy immune system (Usdin, 2005: 13 - 14).

In 1982 public health officials began to use the term "Acquired Immune Deficiency Syndrome" AIDS to describe the occurrence of opportunistic infections. Formal tracking (surveillance) of AIDS case began that year in the United States (NACO, 2006).

The extent to which an infectious disease spreads in a population depends on its reproductive rate, or the average number of susceptible people infected by an infected person I over his or her lifetime. In order for an epidemic to grow, its reproductive rate must be greater than 1, the reproductive rate the more rapidly it will spread. The amount of time a person remains infectious, his or her risk of transmission per sexual contact and the rate of acquisition of new partners all affect the reproductive rate of any STD, including HIV, Biological, behavioral and economic factors influenced these three variables.

Biological Factors

The recent evidence suggests that the average probability of transmission from an infected person to a no infected person (called infectivity) is greatest during two periods of high viral load. The first is primary infection, which occurs during the time between exposure to HIV and the appearance of HIV antibodies. The second is when the person is in the advanced stage of the disease and has developed AIDS (as indicated by a low CD4 T-lymphocytes count). Untreated STD also increases the risk of HIV transmission. Genital ulcer disease increases

the risk of transmission per sexual exposure 10 to 50 times from male to female (Chlamydia and Gonorrhea) increase the risk two to five fold.

Behavioural factors

The rate of partner change, the number of concurrent partners, and mixing patterns influence the reproductive rate. Both the average rate of partner change in the society and the variation across individuals has an influence on the dynamic of the epidemic. The greater the number of partners, the faster the spread of HIV. In almost all societies, most individuals have few sexual partners during their life time and a small number of individuals have many partners. But even a very small group of people with many partners may be enough to sustain epidemic and gradually spread it to the rest of the population. Recent evidence suggests that the number of concurrent partners is more important than the total number of sexual partners, a finding that this important implications for prevention messages. The more mixing between high risk individuals (those with many partners) and low risk individuals (those with few sexual partners), the faster epidemic will spread in the general population. This occurs, for example, in countries with an active commercial sex industry.

Economic Factor,

Poverty, which is endemic in many developing countries, also may increase transmission. For women, being impoverished may make them more vulnerable and less effective in negotiating safe sex with partners, or they may be more likely to engage in sex work. For men, poverty may motivate them to migrate for work, putting them at risk for having more sexual partners while away from the family.

Factors that accompany economic growth, particularly Improved infrastructure and increased travel, may facilitate the spread of the epidemic. One reason is that an open economy / facilitates the movement of individuals, and countries with larger immigration populations tend to have more severe HIV/AIDS epidemics, all else being equal. Economic growth also may contribute to a shift from more conservative to more liberal social attitudes, which may lead to greater individual freedom and more risky sexual activity (Peterson, et al 2000: 225 – 226).

Overview of the spread and control of HIV / AIDS in the world

The spread of HIV / AIDS such that an estimated 38.6 million (33.4 million – 46.0 million) people worldwide living with HIV in 2005, an estimated 4.1 million (3.4 million - 6.2 million) became newly infected with HIV and an estimated 2.8 million (2.4 million – 3.3 million) loss their life to AIDS.

2006 REPORT ON THE GLOBAL AIDS EPIDEMIC*

Regional and HIV statistics and features, 2005 and 2003				
Country	**Adults (15+) and children living**	**Adults (15+) and children**	**Adult (15-49)**	**Adult (15+) and child death due to**
Sub-Saharan Africa				
2005	24.5 million	2.7 million	6.1	2.0 million
	[21.6-27.4	[2.3-3.1 million]	[5.4-6.8]	[1.7-2.3 million]
2003	23.5 million	2.6 million	6.2	1.9 million
	[20.8-26.3	[2.3-3.0 million]	[5.5-7.0]	[1.7-2.3 million]
North Africa and Middle East				
2005	440 000	64000	0.2	37000
	[250 000-720 000]	[38000-210000]	[0.1-0.4]	[20 000-62 000]
2003	380 000	54000	0.2	34000
	[220 000-620 000]	[31 000-	[0.1-0.3]	[18000-57 000]
Asia				
2005	8.3 million	930 000	0.4	600 000
	[5.7-12.5 million]	(620 000-2.4	[0.3-0.6]	[400 000-850 000]
2003	7.6 million	860 000	0.4	500 000
	[5.2-11.3 million]	[560 000-2.3	[0.2-0.6]	[340000-710000]
Oceania				
2005	78000	7200	0.3	3400
	[48000-170000]	[3500-55 000]	[0.2-0.8]	[1900-5500]
2003	66000	9000	0.3	2300
	[41 000-140000]	[4300-69 000]	[0.2-0.7]	[1300-3600]
Latin America				
2005	1.6 million	140000	0.5	59 000
	[1.2-2.4 million]	[100000-	[0.4-1.2]	[47 000-76 000]
2003	1.4 million	130000	0.5	51 000
	[1.1 -2.0 million]	[95000-310000]	[0.4-0.7]	[40 000-67 000]
Caribbean				
2005	330 000	37000	1.6	27000
	[240 000-420 000]	[26 000-54 000]	[1.1-2.2]	[19000-36000]
2003	310000	34000	1.5	28 000
	[230 000-400 000]	[24 000-47 000]	[1.1-2.0]	[19000-38000]
Eastern Europe and Central Asia				

2005	1.5 million	220 000	0.8	53 000
	[1.0-2.3 million]	[150000-6500001	[0.6-1.41	[36 000-75 000]
2003	1.1 million	160000	0.6	28000
	[790 000- 1.7	[110 000-440	[0.4-1.01	[19000-390001
North America, Western and Central Europe				
2005	2.0 million	65000	0.5	30000
	[1.4-2.9 million]	[52 000-98 000]	[0.4-0.7]	[24 000-45 000]
2003	1.8 million	65000	0.5	30 000
	[1.3-2.7 million)	[52 000-98 000]	[0.3-0.6]	[24 000-45 000]
Total				
2005	38.6 million	4.1 million	1.0	2.8 million
	[33.4-46.0	[3.4-6.2 million]	[0.9-1.21	[2.4-3.3 million)
2003	36.2 million	3.9 million	1.0	2.6 million
	[31. 4-42. 9	[3.3-5.8 million]	[0.8-1.2]	[2.2-3.1 million)

* *Sources: UNAIDS Report, 2006*

Sub – Saharan Africa

Sub – Saharan Africa remains the worst affected region in the world. Across the region, rate of new HIV infections peaked in the late 1990s and a few of its epidemics show recent declines notably in Kenya, Zimbabwe and in urban areas of Barkina Faso. Overall HIV prevalence in this region appeared to be leveling off albeit at exceptionally high levels in southern Africa. Such apparent stabilization of the epidemic reflects situations where the number of people being newly infected with HIV roughly matches the numbers of people dying of AIDS related illness.

A little more than one-tenth of the worlds population live in Sub – Saharan Africa which is home to almost 64% of all people living two million HIV – 24.5 million (21.6 million – 27.4 million) younger man 15 years of age. Indeed nine in ten children (younger than 15 years) living with HIV one in Sub – Saharan Africa. An estimated 2.7 million (2.3 million – 3.1 million) people in the region became newly infected while 2.0 million (1.7 million – 2.3 million) adults and children died of AIDS. There were some 12.0 million (10.6 million – 13.6 million) orphans living in Sub – Saharan Africa in 2005.

Asia

Latest estimate show some 8.3 million (5.7 million – 12.5 million) people (2.4 million among adult) women (1.5 million – 3.8 million) were living with HIV in Asia, an estimated 180000 (75000 – 390000) children were living with HIV. Approximately 930000 (620000 – 2.4 million) people were newly infected with HIV in 2005, while AIDS claimed approximately 600000 (400000 – 850000) lives.

Oceania

Over all, an estimated 78000 people (48000 – 170000) in Oceania were living with HIV at the end of 2005, including 7200 (3500 – 55000) people who acquired HIV in that year. Regional adult HIV prevalence was approximately 0.3% (0.2% - 0.8%), mainly due to the epidemic in Papua New Guinea.

Eastern Europe and Central Asia

The epidemic in Eastern Europe and Central Asia continue to expand. Some 220000 (150000 – 650000) people were newly infected with HIV in 2005, bringing to about 1.5 million (1.0 million – 2.3 million) the number of people living with HIV – a twenty – fold increase in less than a decade. Between 2003 and 2005 the number of adults and children living with HIV in this region increased by more than one third.

The epidemics death toll is rising sharply too. AIDS killed an estimated 53000 (36000 – 75000) adults and children in 2005 – almost twice as many as in 2003. Increasingly large numbers of women's are being infected with HIV. In 2005, an estimated 420000 (270000 – 680000) women aged 15 years and older were living with HIV – one third more than the 310000 (20000 – 490000) in 2003.

Caribbean

A total of 330000 (2400000 – 420000) people are living with HIV in the Caribbean, 22000 (9800 – 43000) of their children younger than 15 years. An estimated 37000 (26000 – 54000) people became infected living with HIV in 2005. Women comprise 51% of adults living with HIV. The Caribbean's epidemics and countries, AIDS responses very considerably in extent and intensity.

Latin America

In Latin America, some 140000 (100000 – 420000) people were newly infected with HIV in 2005, bringing to 1.6 million (1.2 million – 2.4 million) the number of people living with virus. There are about 32000 (19000 – 59000) children younger than 15 years living with HIV. In 2005 AIDS claimed some 59000 (47000 – 76000) lives. Approximately 294000 people were receiving antiretroviral therapy in this region at the end of the 2005 – 73% of the estimated 404000 people in need of treatment

North America, Western and Central Europe

Overall in these regions approximately 65000 (52000 – 98000) people were newly infected with HIV in 2005, bringing to 2.0 million (1.4 million – 2.9 million) the number of people living with HIV. AIDS deaths in 2005 were comparatively few, about 30000 (24000 – 45000) a consequence of widespread access to antiretroviral therapy.

Across the Atlantic, an estimated 720000 (550000 – 950000) were living with HIV in 2005 in Western and Central Europe, where heterosexual intercourses has become the main mode of transmission of new HIV infections in several countries. Accordingly, growing proportion of new HIV diagnoses are in women – roughly one – third in those countries with new data for 2004 or later. (unaids;2006:8 - 45)

Joint UNAIDS Control Policy

The steady growth of H1V prevalence throughout the world stems not from the deficiencies of available prevention strategies and tools but' rather from the failure to use them. At present, there are more HIV infections every year than AIDS-related deaths. The trends in increasing infections pose a major threat to the global response to AIDS.

Effective HIV prevention programming focuses critical relationships between the epidemiology of HIV infection, the risk behaviours that transmit HIV, and the cultural, institutional and structural factors that drive] risk behaviours. Risk behaviours are enmeshed in complex webs of economic, legal, political, cultural and psychosocial determinants that must be analyzed and addressed by policies that are also effectively implemented and through scaled-up programming.

Effective prevention efforts focus on measures that directly support risk reduction by providing information and skills as well as access to needed commodities (such as condoms, clean injecting equipment, and drug substitution therapy) for the populations most in need. Prevention programming also addresses the collective social and institutional factors, such as sexual norms, gender inequality, and HIV related stigma that will otherwise continue to fuel HIV. Planners develop a comprehensive range of services and other measures, but design them to be delivered to the people and in places that will make a

difference in containing HIV. In sum, national planners and policy makers must: (1) Know their epidemic; and (2) Set priorities accordingly

The prevention and treatment must be scaled up in a balanced way, to capitalize fully on synergies between the two. Comprehensive HIV prevention requires a combination of problematic intervention and policy action that promote safer behaviours, reduce biological and social vulnerability to transmission, encourage use of key prevention technologies, and promote social norms that favour risk reduction.

HIV prevention includes addressing an array of issues discussed in other thematic areas in the policy services. HIV prevention programmes, and legal services for women, can also contribute to intensification of HIV prevention. Strong linkages as well as special efforts to reach those at higher risk and excluded from, access to services will result in more effective programmes with greater impact

Essential Policy Actions for HIV Prevention

1. Ensure that human rights are promoted, protected and respected and that measures are taken to eliminate discrimination and combat stigma.

2. Build and maintain leadership from all sections of society, including governments, affected communities, (nongovernmental

organizations, faith-based organizations, the education sector, media, the private sector, and trade unions.

3. Involve people living with HIV, in the design, implementation and evaluation of prevention strategies, addressing the distinct prevention needs.

4. Address cultural norms and beliefs, recognizing both the key role they may play in supporting prevention efforts and the potential they have to fuel HIV transmission.

5. Promote gender equality and address gender norms and relations to reduce the vulnerability of women and girls, involving men and boys in this effort.

6. Promote widespread knowledge and awareness of how HIV is transmitted and how infection can be averted.

7. Promote the links between HIV prevention and sexual and reproductive health.

8. Support the mobilization of community based responses throughout the continuum of prevention, care and treatment..

9. Promote programmes targeted at HIV prevention needs of key affected groups and populations.

10. Mobilizing and strengthening financial, and human and institutional capacity across all sectors particularly in health and education.

11. Review and reform legal frameworks to remove barriers to effective, evidence based HIV prevention, combat stigma and discrimination and protect the right of people living with HIV are vulnerable or at risk to HIV.

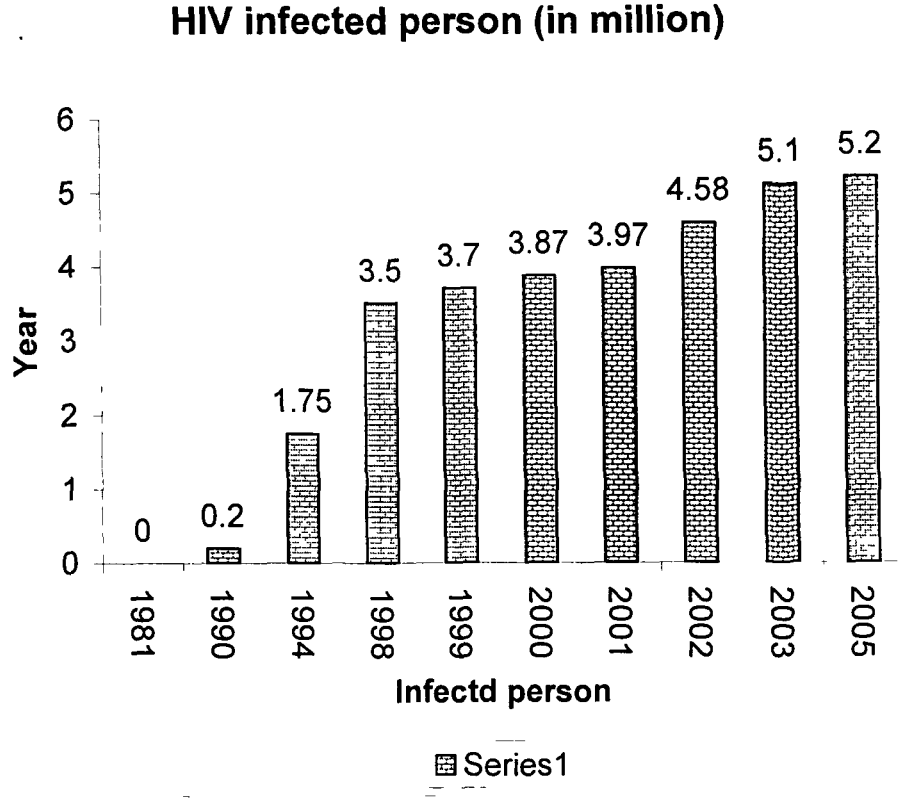
12. Ensure that sufficient investments are made in the research and development of, and advocacy for, new prevention technologies (UNAIDS, 2006).

The emergence, spread and control of HIV in India

The earliest case of suspected HIV in India was reported in August 1984. The patient was a blood donor who used to visit Female Sex Workers (FSWs) in Vellor, Tamil Nadu. His HIV infection was suggested because serological testing for HIV was initiated in India only in October 1985 at the Christian Medical College, Vellore and National Institute of Virology, Pune. The first serologically confirmed HIV infection was declared in 10 of 102 FSWs tested in Madras in February 1986. the first AIDS case in India was reported in May 1986 – about years after AIDS became clinically evident in USA and Europe. It was the case of a person who lived in Bombay but was affected by blood transfusion during coronary by-pass surgery in USA. The second case

reported a month later, was a hemophilic patients who had also received blood transfusion in the USA (Nag, 1996: 5 – 7)

India is the second most populace country in the world but now is going to become second AIDS capital of the world. In India, an estimated 5.2 million people in the 15 – 79 year age range were living, with HIV in 2005. While in the number of infected people in India was test 0.2 million 1990, but the figure was risen to 5.2 million in 2005. Similarly, the number of AIDS in country has risen from 102 in December 1992 to 103857 in March 2005.

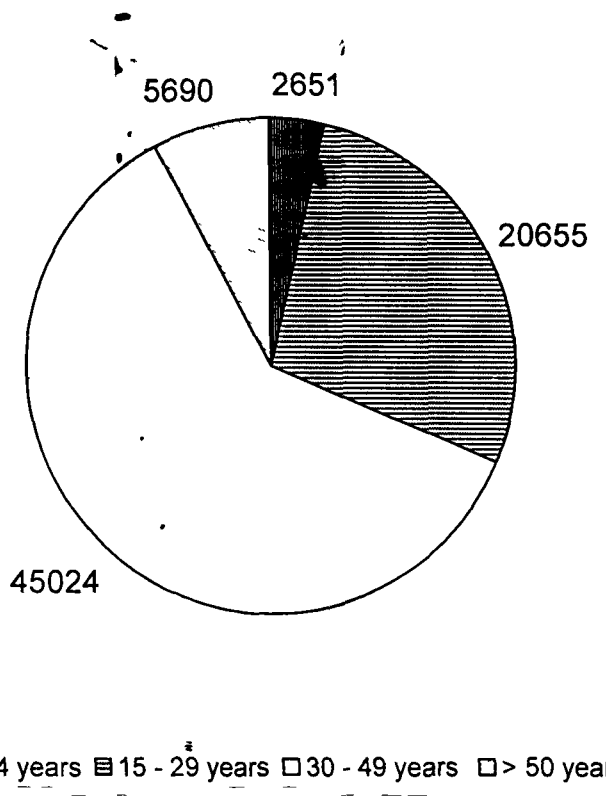


Number of estimated as HIV infected (in million)

Category	Number of cases	Percentage
By sexual	89064	85.76
Prenatal	3713	3.58
Through infected syringe/needle	2649	2.55
Through blood and blood product	2113	2.03
Others not specified	6318	6.08
Total	103857	100

Probable route of HIV infection in India: 31st March 2005

Source: NACO, India 2005



Age sex distribution of HIV cases in India: 31st March 2005

Source: NACO, India 2005

The analysis of the route of the infection of these 103857 cases shows that the majority is infected by sexual route (85.76%) only minority is infected by prenatal route (3.58%), by infected syringe of needle (2.55%), by blood and blood products (2.03) and by other not specified (6.08%).

The analysis of the age and sex distribution of these 103857cases also shows that the disease affects the youth and middle age people

which the productive and reproductive age group. As there are 92125 in the age group 15 – 49, the disease affects men more than women, as there are 65679 males as compared to only 26426 females in the age group of 15 to 49.

NACO divided sates into two types in terms of HIV / AIDS. High prevalence state and low prevalence states, when the HIV prevalence in any states is five percent or more among high risk groups (like commercial sex workers, MSMs, and those attending sexually transmitted disease (STD) clinics and 1% or more among the low risk population (like women attending antenatal clinic). Then the state is considered to be in high prevalence. High prevalence states are Andhara Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland (Pradhan, 2005:8).

What makes India vulnerable HIV / AIDS

1. Poverty
2. Vast country with varied socio-economic norms
3. Very low levels of literacy in certain part of India contributing to perpetuation of myths and misconceptions
4. Huge migrant population

5. Untreated sexually transmitted infection (STI). Due to lack of awareness, hesitation and also lack of access to health care systems

6. Vulnerability of women to HIV, especially due to gender inequality (UNAIDS, 2004).

National AIDS and Prevention Control Policy

OBJECTIVES AND GOALS

The general objective of the policy is to prevent the epidemic from spreading further and to reduce the impact of the epidemic not only upon the infected persons but also upon the health and socio-economic status of the general population at all levels. The policy envisages effective containment of the infection levels of HIV/AIDS in the general population in order to achieve zero level of new infections by2007. The specific objectives of the policy are:

1. To reiterate strongly the Government's firm commitment to prevent the spread of HIV infection and reduce personal and social impact.

2. To generate a feeling of ownership among alt the participants both at the Government and non-Government levels, like the Central Ministries and agencies of the Government of India, State Governments, city corporations. industrial undertakings in

public and private sectors, *panchayat* institutions and local bodies to make it a truly notional effort

3. To create an enabling socio-economic environment for prevention of HIV/AIDS, to provide care and support to people living with HIV/AIDS and to ensure protection/promotion of their human rights including right to access health care system, right to education, employment and privacy to mobilize support of large number of NGOs/ Community Based Organizations (CBOs) for, an enlarged community initiative To prevention and alleviation of the HIV/AIDS problem.

4. To decentralize HIV/AIDS control programme to the field level with adequate financial and administrative delegation of responsibilities.

5. To strengthen programme management capabilities at the State Governments, municipal corporations, panchayat institutions and leading NGOs participating in the programme.

6. To bring in horizontal integration at the implementation level with other national programmes like Reproductive and Child Health, TB Control, Integrated Child Development Scheme and with the primary health core system.

7. To prevent women, children and other socially weak groups from becoming vulnerable to HIV infection by improving health education, legal status and economic prospects.

8. To provide adequate and equitable provision of health care to the HIV-infected people and to draw attention to the compelling public health rationale for overcoming stigmatization, discrimination and seclusion in society.

9. To constantly interact with international and bilateral agencies for support and cooperation in the field of research in vaccines, drugs, emerging systems of health care and other financial and managerial inputs.

10. To ensure availability of adequate and safe blood and blood products for the general population through promotion of voluntary blood donation in the country.

11. Promote better understanding of HIV infection among people, especially students, youth and other sexually active sections to generate greater- awareness about the nature of its transmission and to adopt safe behavioural practices for prevention.

STRATEGY

A. The national AIDS control policy principally aims at the following strategy for prevention and control of the disease:-

1. Prevention of further spread of the disease by making the people aware of its implications and provide them with the necessary tools for protecting themselves.

2. Controlling STDs among vulnerable sections together with promotion of condom use as a preventive measure.

3. Ensuring availability of safe blood and blood products; and

4. Reinforcing the traditional Indian moral values among youth and other impressionable groups of population.

(B). To create an enabling socio-economic environment so that all sections of population can protect themselves from the infection and families and communities can provide care and support to people living with HIV/AIDS.

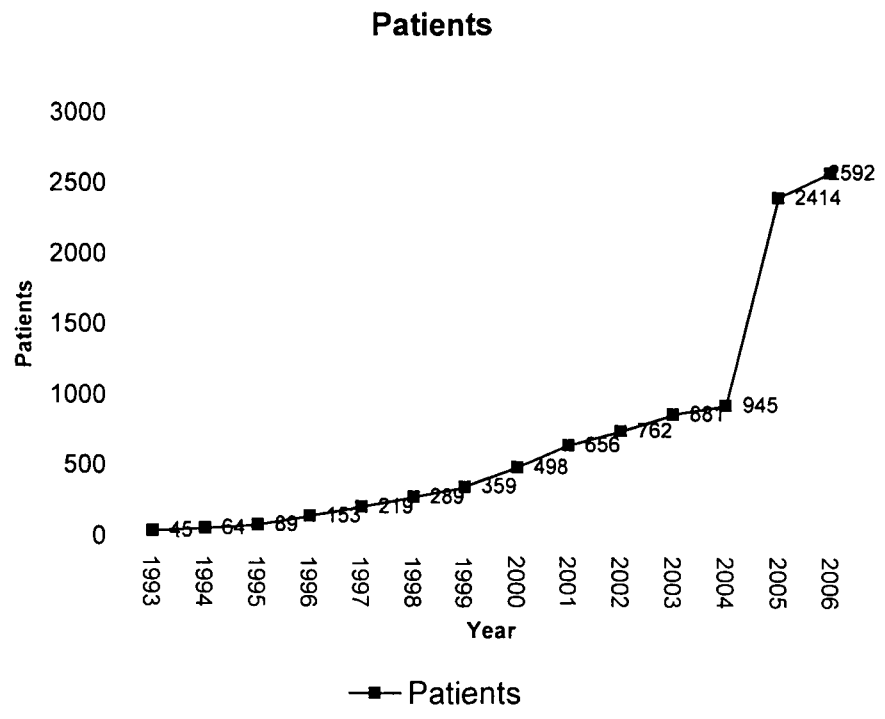
(C) Improving services for the care of people living with AIDS in times of sickness both in hospitals and at homes through community healthcare.

HIV / AIDS in Delhi

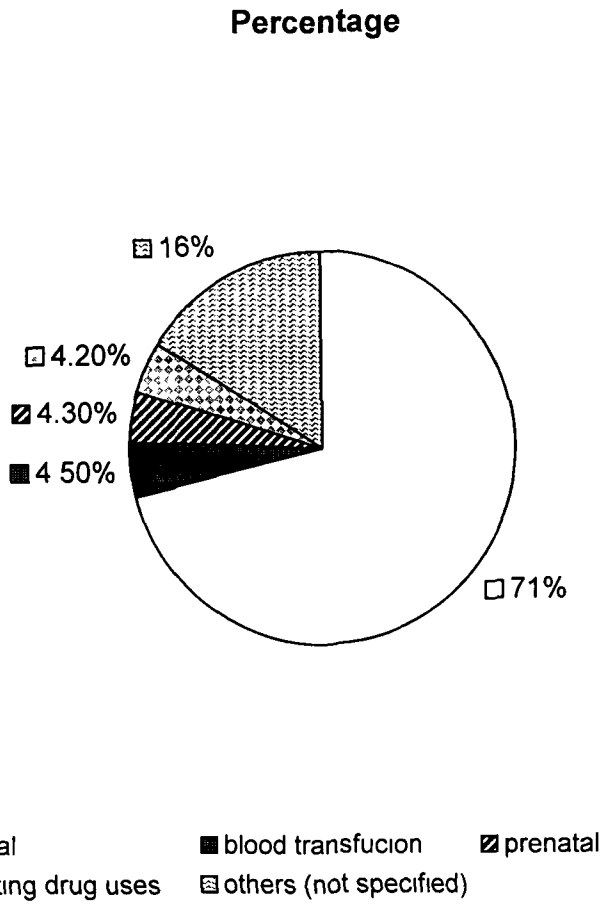
In Delhi first AIDS case was reported in the year of 1998 and the number of AIDS cases has risen from 45 in 1993 to 2592 in January 2006 (DSACS, 2006).

In Delhi, the proportion of HIV transmitted through sexual contact 71%, is lower than that of all India at 85.76 percent. Transmission by blood transfusion and blood products is about 4.5% as compared to 2.03 %, at National level, prenatal transmission is 4.3 as compared to 3.58 at national level and through injection drug users is 4.2 % as compared to 2.55 at national level and 16% others are (not specified) as compared to 6.08 at national level (DSACS, 2006).

Distribution of AIDS cases in Delhi up to January 2006



Mode of Transmission base on data from AIDS cases in Delhi up to January 2006



CHAPTER – 4

The Field Setting and Research Design

The universe of study:

The present study deals with the problems of the rehabilitation of people living with HIV / AIDS (PLWHA) in Delhi. The universe of study is Delhi, National Capital of India (NCI. In 1911 Delhi became the center of all activities after the capital was shifted from Kolkata. It was made a union territory. In 1956 it was made a state. In 1991 Delhi has been noted for its very rate of population growth since the 1951 census, when Delhi's population numbered 1.74 million, the total has growth at more than twice the national rate. Between the 1991 to 2001 census the population of National capital territory (NCI) of Delhi grew from 9.42 to 13.85 million. The population increase in ten years is around 4.43 million. Delhi is surrounded by Haryana all the sides, except the East when its borders with Utter Pradesh. Delhi is located 28.38^0 North latitude and 77.12 East longitude (India:2006).

The Delhi as been selected as the universe of study because, as the capital of India, it occupies a prominent place as the industrial and commercial hub of North India. It has a fast growing population because number of migrant from the adjoining states. This large scale migration has brought in it wake unplanned development, disparities in living standard and proliferation of slums and resettlement colonies. This dream city for many is also a center of 35,000 street children and 10,000 intravenous drug users (DSACS:2005). Large number of traders of flesh, long route truck drivers and transport works and refugees from

Bangladesh and Nepal. The presence of migrants, CS workers, street children, intravenous drug users, truck drivers and transport workers and refugees, many of whom are poor and illiterates makes Delhi highly vulnerable to HIV / AIDS.

Research Design

The term 'design' means, "drawing an outline or planning or arranging details". It is process of making decision before the situation arises in which the research has to be carried out. Research Design (RD) is thus a detailed plan of now the goals of research will be achieved.(Ahuja;2003:120) William Zikmund, (1998:41) has described R.D. is a master plan specifying the method and procedure for collecting and analyzing the needed information.

As researcher differs in terms of purposes, designing can not be uniform. The rehabilitation of HIV / AIDS is a problem which has hitherto remain unexplored and there is need for exploratory research design is mainly concerned with gaining familiarity with a problem or to formulate it more precisely carried out when there is not sufficient information available about the issue to be studied or in other words the researcher has either no knowledge or limited knowledge (Wilkins and Bhandakar;1988, 103 -104)

Sellitiz Jahoda and Cook (1966:53-60) have suggested the procedure of exploratory research as consisting of the following three stages.

1. **Survey of literature:** Out of the singlest ways of economizing effort in unexploratory inquiry is to review and build upon the work already done by others. The focus of research is review of secondary sources that it may serve as leads for further investigation. This includes defining rehabilitation in the context of HIV / AIDS patients and explaining the dimension of rehabilitation.

2. **The Experience survey:** Probably only a small portion of existing knowledge and experience is ever put in to written form. In this study such experience person in the area like counselors, directors of NGOs, social workers and concern government officers who are key informant are likely to give insight into the problem under investigation. It is the purpose of such experience survey together and synthesize such experience which would serve as guide in research. The knowledge of the key informant was collected through conversation with them on the area of their specialization.

3. **The analysis of insight stimulating examples:** The scientist working in relatively unformulated areas, where

there is little experience to serve as guide, have particularly fruitful method for stimulating insight and suggesting hypothesis for research. They used the case study method with a view of describing qualitative aspect of social life, which can not be captured merely by statistical methods. This method is useful in describing characteristic of whole unit by studying few cases to assume that they represent the whole unit (Goode and Hatt:314).

Following the procedure laid down the Settitez, Zahoda and Cook, the review of the secondary sources is made first and this followed by the experience survey of four key informant which are a counselor, director of NGOs, social worker and concerned government officer. This is followed by the intensive study of selected cases and participant observation of rehabilitation within the family, friend circle, community, work place and in the health sector. There are 3 community cum center run by NGOs which are attached with Delhi Government in which there were hundreds and fifty beds of which 90 were occupied by HIV / AIDS patients. 25 cases were selected from these care center. For the purpose of counseling case studies with the help of key informant.

Objective of the Study:

1. To study the pattern of spread of HIV / AIDS in Delhi.

2. To study government policies for rehabilitation of HIV / AIDS patients in Delhi.

3. To examine the problem of HIV / AIDS patients in getting care and treatment at hospitals in Delhi.

4. To examine the role of NGOs and its services for rehabilitation of HIV / AIDS patients in Delhi.

5. To examine the discrimination of HIV / AIDS patients in Delhi in their families, friend circle, community and coworkers at work place.

6. To suggest guide lines and policy implementation for an action strategy for the effective rehabilitation of HIV / AIDS patients.

Fieldwork is the most crucial as well as difficult part of the research procedure. The success of field work depends on the confidence created by the investigator to the respondent. The problem that emerges is to obtain continued acceptability and rapport for proper response. The

draw back with a HIV / AIDS patients was that they were reluctant to answer the question about their personal and family matters. It is only when, they were directed by a counselor of the care center that they agreed to be interviewed. Most of the respondent were very cooperative when it was explained to them that it was a purely academic study and had nothing to do with governmental matters and their personal identity and other information would be held strictly confidential. For the purpose of interview their local language was used as a medium of conversation and every item of the interview schedule was explained to the respondent. Wherever, they get difficulty to understand its meaning and contents. At the out set, some questions of general nature were asked and gradually they were reconciled to more personal questions. This technique made that (PLWHA) feel relieved so as to reveal fact more comfortably.

CHAPTER – 5

Rehabilitation of HIV / AIDS patients

Rehabilitation of HIV / AIDS patients

The present study deals with the problem of the rehabilitation of people (PLWHA) in Delhi. Rehabilitation involves enabling them to live a normal pattern of life with dignity.

1. **Wolfensberg** define rehabilitation as "utilization of means which are as culturally normative as possible in order to establish and for maintain behaviour and characteristic which are as culturally normative as possible (quoted in Pilling;1991:14).

2. Another definition given by Benntt as "the process of helping a physically or psychiatrically disables person to make the best use of his residual abilities in order to function in as normal an environment as possible (quoted in Pilling;1991:14).

These two definitions apply only to physically or mentally disable persons but a third definition is more comprehensive.

Anthony says, "Philosophically rehabilitation is directed at increasing the strengths of clients so that they can achieve their maximum potential for independent live and meaning of full careers (quoted in Pilling;1991:14).

Rehabilitation of HIV / AIDS patients therefore involves the two aspects of supporting the patients and enabling his adjustment in society.

While prevention of HIV / AIDS remain high priority, there is great challenge in confronting need for rehabilitation of people living with HIV / AIDS. The rehabilitation of HIV / AIDS patients has dimensions.

1. Provision of care, treatment and support, which is largely a medical dimension. And

2. Adjustment within the family, community and workplace, which is a social dimension.

Since care and treatment needs are expanding rapidly, the current treatment facilities can provide service to only small percentage of HIV / AIDS patients.(unaids;2003:15) Another reason for expanding the facilities for care, treatment and support of HIV / AIDS patient is ARTs. ARTs, has several drawbacks. They are very expensive and as they have to be taken life long, they are beyond the reach of most person. Secondly, they are highly toxic and could cause pain and unfamiliar forms of discomfort. Further ART drugs require strict adherence to complex protocols for administration. The number and combination of doses, the time of day for intake. They also require regular monitoring test in order to fine tune further administration and importantly check for drug resistance.(ramasubban;2005:43) It is possible for people to live fairly long lives just as they would in the case of any chronic disease, provided that Art is administered in a timely manner. Therefore, it is necessary to make provision of comprehensive HIV / AIDS care and treatment which integrates the existing health infrastructure consisting of care center run by NGOs, drop – in – center, public health facilities, private clinic and network of PLWAH.

More efforts should be directed to get private sector to participate in activities involving care and support of HIV / AIDS patients. It is also necessary that the family and community resource are fully utilized so as to increase their capacity to care for HIV / AIDS patients to reduce the load on health facilities.

This system of care and treatment must be link to support system through counseling and testing centers. These counseling and testing center will provide a supportive environment for HIV / AIDS patients so that they remain in the main stream. Before the test, the person must receive pre test counseling. This includes complete information about the nature of the disease including factors in his own life that might have caused exposure to the infection, the nature of the test itself, negative or in determinate. If the persons test is positive, he must be mandatory be offered 'post test counseling' that maintains the confidentiality of the persons positive status. Post test counseling is meant to help the person come to terms with the diagnosis, learn how to make responsible changes in life style and how to take care of himself particularly in terms of nutrition and treatment for opportunistic infections (Ramasubban et al. 2005:5)

Psychological support, including stress and anxiety reduction, promoting positive living and helping individuals to make informed decisions about HIV testing planning for the future impact on family members and behaviour change aimed at presenting HIV transmission to sexual partners (WHO;1998:3-11).

It goes without saying that HIV / AIDS is as much social concern as a medical concern because the disease is also associated with stigma and discrimination against HIV / AIDS patients. Un-aids characterizes HIV related discrimination that may follow as the unfair and unjust treatment of an individual based on real or perceived HIV status. They

face discrimination in family, community, work place and health sectors when they need support the most. People affected by HIV / AIDS have experience alienation from their spouses and families rejection by one communities, stringent from friends and compatriots, denial of medical treatment and refusal to perform last rites (Pradhan;2005:135).

Erving Goffman is widely credited for conceptualizing and crating a frame work the study of stigma. Goffman (1963:3) described stigma as "an attribute that is deeply discrediting within a particular social interaction. According to Goffman disease is associated with the highest degree of stigma share common attributes.

1. A person with the disease is seen as responsible for having the disease.
2. The disease is progressive and incurable.
3. The disease is not well understood among the public.
4. The symptoms can not be concealed. HIV / AIDS has features that carry a high (level)degree of stigma.

First: People affected with HIV are often blamed for their condition and many people believe HIV could be avoided if individual made better moral decision.

Second: Although HIV is treatable, it is nevertheless a progressive, incurable disease.

Third: HIV transmission is poorly understood by some people in the general population causing them to feel threatened by the mere presence of the disease (UNESCO:2003).

Finally: Although a symptomatic HIV infection can often be concealed, the symptoms of HIV related can not. HIV related symptoms might be considered repulsive, ugly and disruptive to social interaction. Thus, stigma associated with HIV / AIDS because a person is having it is held responsible for it, it is progressive and incurable, it is not well under stood the public and symptoms can not be concealed (Pradhan et al 2005:135).

Attributes of HIV / AIDS associated with stigma:

1. HIV is life threatening and hence people are scared of contacting the virus.

2. While a social rejection of certain social group (e.g. homosexual, sex workers, injecting drug users and migrants) may predate HIV / AIDS the disease has in many cases, reinforced this stigma.

3. Unlike other leading causes of mortality, HIV selectively affects young adults, the most productive and reproductive members of society. The effects of ill-health and death among these individuals are amplified because of their dependents.

The rehabilitation of HIV / AIDS patients is very important because the stigma and discriminating against HIV / AIDS patients will endangers non - HIV / AIDS persons. It will send a clear signal to HIV / AIDS patients whose behaviour put them at risk of HIV infection to hide or otherwise avoid being identified (Jaiswal;1992:105).

CHAPTER – 6

Case Study of Key Informants

Key informant No. 1

Counselor of Care Center

The rehabilitation of HIV / AIDS patients is very important because they way in which the non - HIV / AIDS patients will make the difference between success and failure of HIV / AIDS prevention. The protection of rights of non - HIV / AIDS persons is best serve through the protection of rights of people who have HIV / AIDS. The human right dimension of HIV / AIDS are far reaching. They have the right to be free from discrimination, the right to information, confidentiality and privacy, sexual autonomy and the right to accessible and affordable medicine, the right to life and health. All the rights are under threat.

Organization and networking of HIV / AIDS patients must be encourage so that they can give voice to their grievance and increase their social adjustment. It will serve as support system in order to campaign against stigma and discrimination in the family, friend circle, community, work place and health sector. This empowerment will also enable them to fight for their right to education, employment, and social security. The case of rehabilitation of HIV / AIDS patients will be strengthen by using their NGOs for providing rehabilitation. Such NGOs must employee HIV / AIDS patients to help other HIV / AIDS patients.

The information education communication campaign of NACO is not reaching the gross-root level. Despite all the talk about funds being

available for IEC, the fact is that funds are in fact quite meager considering the size of the country and the magnitude of the problems. This is because the campaign is run at two levels of the nation and of states but there is need for further decentralization, unless the *panchayats* at the Block and village level are involved in the campaign, it will not have the desire result.

Voluntary Counseling & Testing Centre (VCTC) is not a place just for testing a sample for HIV but much more than that. One of the basic element involves is a confidential discussion between the clients and the trained counselor and the focus is on emotional and social issues related to possible or actual HIV infection. The aim of the VCTC is as follows:

1. Earlier access to care and treatment.

2. Providing factual information about HIV / AIDS and clearing misconception.

3. Reduction of fear by providing emotional support through counseling.

4. Advising improvement of health through good nutrition.

5. Motivation to initiate or maintain safer sexual practice and behaviour change.

6. Prevention of opportunistic infections through proper administration of ART.

Key informant No. – 2

Directors of NGOs

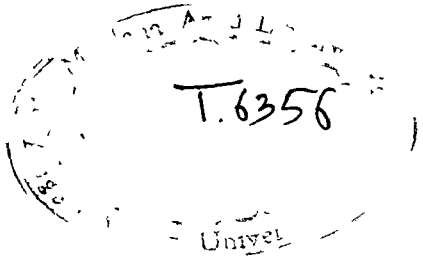
The NGOs have an important and very special role in spreading awareness about HIV / AIDS intervention necessary for prevent, care, treatment and support of HIV / AIDS patients. NGOs are not under some political constraints as government programmes and so they have greater flexibility and the capacity to accommodate change programme according to public needs and implements new initiative easily.

The death of the HIV / AIDS patients creates many problems for the care center or hospital staff, in some cases there is no family member to take care of dead body. Even when there is family member, in most cases they do not want to take it back home for cremation because the stigma attached with disease will adversely affects the rejection of the family. So they want to cremate the body in Delhi itself and they leave it for the care center or hospital staff. The HIV / AIDS patients not only face stigma and discrimination in their life time but it also continue even after their death. The government gives only Rs. 500/- for cremation of the dead body of HIV / AIDS patients and this amount is not sufficient

even for transporting the body to the cremation ground. Stigma and discrimination take such form as refusal to life the body after death not getting transported facilities as well as the facilities to keep the dead body in a mortuary, denial of the use of common cremation ground and performance of last rites.

The negative reaction of the community is not only against HIV / AIDS patients but also their families. Till the death of their parents and those who take care of HIV / AIDS patients. The family members also feel avoidance and rejection by neighbors and the staff who care for HIV / AIDS patients are also regarded with distrust and suspicion.

In Delhi 70 percent people are infected through unprotected multiple partner sexual relation. The Commercial Sex Workers (CSWs) are one of the major agent for spread of HIV / AIDS in Delhi. There work must be legalized and there periodic medical examination must be made compulsory. Those who are HIV positive must not be allowed to continue as C.S.Ws. The government and voluntary organization must ensure the alternative sources for income generation to such commercial sex workers.



Key informant – 3

Social worker

Although the Delhi is not counted in the high prevalence state, the problems of HIV / AIDS is becoming issue at present. Delhi is mega city in which different people coming from many states in search of livelihood and job. They are away from their families for a long period of time. They are mostly poor and illiterate people staying in slum areas ands involve in high risk behaviour such as unprotected, multiple partner sexual relations with CSWs, homosexuality and injecting drug use. The youth particularly, those in modern occupation such as work in call centers are also involves in high risk behaviour. Due to westernization trends are fast changing among youth and there is increasing generation gap. Parental authority has declined and sexually permissive culture and pre marital sex is rising among youth in Delhi.

It is work of media and NGOs to spread the awareness about nature and causes of the disease. The only way to remove discrimination is to clear the misconception about the disease such as that it spread through breathing, smoking, hand shaking hand, sitting near by, using same utensils, sharing same toilet seats. The awareness campaign of the government reaching only the educated people in urban areas. Since HIV / AIDS affects more illiterate people in slums and rural areas, it is necessary to spread the message to these sections.

The government is not providing adequate funding for care, treatment and support for HIV / AIDS patients. These funds are inadequate because the government does not have proper statistics about the number of HIV / AIDS patients. The government should provide good resource, better environment, and adequate expert staff. The government must provide adequate funding for free testing facilities; free medication and proper nutrition should be top priority of the government. Let us we not talk but do something for them.

There must be provision of testing centers, trained nurses and experienced doctors, it is poor state of the health delivery system in India which prevents the care and treatment of HIV / AIDS patients. There is no question that health services in India need a complete over haul as it has suffered from cuts under structural adjustment programmes. It must be realized that the care and treatment and also rehabilitation of HIV / AIDS patients is necessary at present because failure to do so will lead to further spread of the disease in the care and treatment of which it is likely that the health delivery system will collapse. The cost of care, treatment and rehabilitation of HIV / AIDS patients must be weighted up against the cost not giving it at present.

Key informant No. – 4

Directors of NACO

The goal of NACO is to prevent new HIV infection over the next five year by integrating programme for preventing, care, support and treatment. The programme lays greater stress on care, support and treatment services.

This will include management of opportunistic infections especially the control of tuberculosis among PLWHAs, clinical diagnosis, ART, community out reach for treatment adherence and psycho-social support through counseling programmes and establishment and support of community care centers are among other majors.

In this way the programme will emphasize the rehabilitation of HIV / AIDS patients integrated with prevention through expanding the services such as the ART is now made available only 54 centeres, which will cover 101 centers (Integrated counseling & testing centers) will expand from 2815 to 4955. the community care centers expand from 122 to 350, the voluntary blood collection is 52% to 90%, condom outlets 6 lakhs to 30 lakhs. The condoms sale's volumes are from 1.6 billion pieces to 3.5 billion pieces. The present patients on ART is 32744 which will go up to 3 lakhs.

The objective of NACO is thus to:

1. Prevent new infections in high risk group and general population.

2. Increase access to care, support and treatment by PLWHA.

3. Strengthening the infrastructure system and human resource in prevention, care, support and treatment, programmes at the district, state and national level.

4. Strengthening the nationwide strategic information management system.

CHAPTER – 7

Case Studies of HIV / AIDS Patients

Case Study No. – 1

(All the name of the case studies have been changed)

Aradhna Devi is a 38 years old woman who was born in Delhi. She is married and has one daughter, she is housewife and educated up to graduation. Her husband has a business of export and import garments and husband also graduate. Income of her husband is Rs. 1,00,000/- per month. His father is employed in an Army and educated up to 12^{th} class and her mother is housewife and illiterate. She belongs to Khatri caste.

Her route of infection is unprotected multiple sexual relation. She was first admitted to a private nursing home as she was suffering from fever, headache, body ache, weight lose and STD. When there was no improvement in her health, her daughter admitted her in government hospital where she tested HIV positive. She took treatment and recovered from the symptom and went back to her home. She also received counseling before and after the HIV test, which gave her psychological support and confidence that she could live a normal life. She took for a longer period of time and spends more than Rs. 60,000/- for treatment. She arrange from her mother and brother. After five months there was recurrence of the same symptom and she was admitted to a care home because she had no money to pay for her treatment. She is getting free food, free medicine, free accommodation, free blood and regular check

up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital she faced stigma and discrimination. The hospital staff put her in isolated place in a gallery of the ward and restricted her movement. In the care home the staff are very supportive and cooperative. They treat her as family member. They also allow her to move freely around the care center.

She disclosed her HIV positive status to her husband, family members and close relatives. Her husband insulted and neglected her but her daughter gave her support and admitted her to the government hospital and care center. Her parents and her brother are helping her by giving financial support. She did not disclose her HIV positive status to her friend and community because she feels that this would adversely affect the reputation of the family and marriage prospect of her daughter.

Message

Women must be aware of causes and consequences of HIV / AIDS. Women should not have any sexual relation with any person accept her husband. Husband and wife must have love and affection to each other. The government must open more HIV and CD4 count test centers, care center for speedy care and treatment, which also must be free of cost. It must ensure the some income generation alternative for HIV / AIDS patients. It must give ART free of cost for every HIV /

AIDS patients. The women must be made aware of causes and consequences of HIV / AIDS.

Case Study No. – 2

Dharampal is a 46 years old man who is born in Delhi. He is married and has one daughter, his occupation was tailor master but currently he is working in care center with an income of Rs. 2,500/-. He is educated up to primary level and his wife is housewife and illiterate. His father was employed in the railway and educated up to 12^{th} class. His mother was housewife and illiterate too. He belongs to Thakur caste.

His route of infection is unprotected multiple partner sexual relationship. He was earlier T.B. patients and tested HIV positive in the government hospital as he was suffering from respiratory problems, pain in the chest, fever, weight lose and hair lose. He also receives counseling before and after HIV test which gave him psychological support and confidence that he could live a normal life. He was treated in the government hospital around a month and then he was shifted to a care center where he took further treatment. There was an improvement in his health and so he resumes his normal life. Now he is working in another care centre where he is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs.

1200/- for CD4 test count and some money on medicine, which are not available in the care center.

He faced stigma and discrimination in the government hospital. He was denied a bed in the hospital on the pretext of over crowding. When he was crying due to pain in his body, the hospital staff scolded and shouted at him. There was no cooperation towards him by the hospital staff. He feels comfortable after shifting to the care center and says that care centre staff treats him as family members.

He did not his disclose HIV status to his wife and other family members, because he was afraid that they will would be anger and pushed him out of the house. He disclosed his HIV status to his friends who started avoiding him; refuse to shake hand, to sit near him.

Message

The government must open more HIV test center and CD4 count test center and which also must be free of cost for every one. These CD4 count test center also open in the care center, where the patients get more speedy treatment because at present care center are charging Rs. 1200/- for CD4 count. The government must provide alternative for income generation scheme to the HIV / AIDS patients.

Case Study No. – 3

Ajay Kumar is a 27years old man who migrated 10 years ago to Delhi from a village in Bihar, staying in slum area. He is married, auto driver with an income Rs. 3,500/- and illiterate. His father is agricultural labourer and illiterate and his mother is housewife and illiterate also. He belongs to Kurmi caste.

His route of infection is through unprotected multiple partner sexual relationship. He was earlier a T.B. patient. He firstly took treatment in the private nursing home as he was suffering from fever, headache, skin rash, body ache, weight lose and respiratory problem. When there was no improvement in his health he went to a government hospital and was tested for HIV on the basis of history and duration of the disease. He also receive counseling before and after HIV test which gave him psychological support and confidence that he could live a normal life. When he had no money to bear the cost of treatment in the government hospital. He shifted to a care center where he is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital, He faced stigma and discrimination; hospital staff put him in a corner of hospital ward and instructed him not to move from his bed. He said that in the care center

the staff is very supportive and cooperative. They treat him as family member. They also allow him to move freely around the care center.

He disclosed his HIV positive status only to his wife and family members. First his wife shouted at him and his family members ask him to leave the house because they said that there was no money to pay for his treatment. But they became cooperative.

Message

He want some financial help from the government. He said government must open more community care center as well as CD4 count test center, which must be free of cost. People must have safe sex and must use condom.

Case Study No. – 4

Raja a 35 years old man who migrated 15 years ago to Delhi from village of Madurai of Tamil Nadu, stayed in slum area. He is divorcee. He use to work as labourer and currently he is working in a care center as sweeper with an income of Rs. 1,500/- and he is illiterate. His father is labourer and illiterate and his mother is housewife and illiterate also. He belongs to Valmiki caste.

His route of infection is through unprotected multiple partner sexual relationship. He was earlier a T.B. patient. He firstly took

treatment in the private nursing home as he was suffering from respiratory problem, fever, headache; skin rash, body ache and weight lose. He also receives counseling before and after HIV test which gave him psychological support and confidence that he could live a normal life. He spend more than Rs. 30,000/- for his treatment because he has been taking treatment for over 10 years. Now he is in care center where he is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital, he faced stigma and discrimination. He was denied a bed in the hospital on the pretext of over crowding and after admission he was placed in an isolated ward and his moment was restricted. There is no stigma and discrimination in care center.

His disclosed his HIV positive status to every body including his wife, other family members, friends and neigbhours. His wife shouted at him and then divorced him in anger. His family member misunderstood and embraced at first but later cooperated with him. His friends refuse to talk to him and started avoiding him and did not share *Bidis* and tea with him as they use to before. His neighbours were so strange from him that they told him to leave the area and go to live with those from whom he got the infection.

Message

People must be faithful to their wife to prevent HIV / AIDS and use of condom must be encouraged among migrants. The government must provide some alternative means for income generation to the HIV / AIDS patients. The government should open more HIV test and CD4 count centers for the speedy care center and treatment. The people must be aware of the causes and consequences of HIV / AIDS.

Case Study No. – 5

Raghu Raj is a 40 years old man who migrated 18 years ago to Delhi from a village of Mainpuri district of UP and staying in slum area in Delhi. He is married and has four children and work as labourer in Sabzi Mandi with an income of Rs. 2,500/- per month and illiterate. His wife is housewife and illiterate. His father is labourer and illiterate and his mother is housewife and illiterate toll. He belongs to Thakur caste.

His route of infection is through unprotected multiple partner sexual relationship. He was earlier a T.B. patient. First he consulted private doctor as he was suffering from respiratory problem, fever, headache; skin rash, body ache and weight lose. He spent more than Rs. 20,000/- which he arranged from his relatives. When there was no improvement in his health, he was admitted in the government hospital

and tested HIV positive and also receive counseling before and after HIV test which gave him psychological support and confidence that he could live a normal life. He took treatment and came out of bed. After a few months he again fell ill with the same symptoms and now had no money even to bear the cost of transportation to the hospital. He shifted to care center. Now he is in care center where he is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital, he faced stigma and discrimination. The hospital staff insulted and scolded him to keep him at a distance and neglected him whenever he asked for some thing. He faced no stigma and discrimination in the care center. The doctor and nurses regularly visit the care center and give proper care and attention.

He disclosed his HIV positive status to his wife and friends. His wife first reacted with disbelief and anger but later cooperated with him. When he disclosed his HIV positive status to his close friends, they insulted him and also told the other people about him. His friends refuse to shake hand, sit near him, tea and food with him.

Message

He wants some financial help from the government. He said government must open more community care center as well as CD4 count test center, which must be free of cost. He also said that people must be faithful to their wife and this is the only way to prevent HIV / AIDS.

Case study No – 6

Kamlesh is a 30 years old man who belongs to a village of Hissar district of Haryana. He is married and his occupation is truck driver on long route with an income of Rs. 6500/- per month. He is educated up to 10^{th} class and has two children. His wife is housewife and also educated up to 8^{th} class. His father is farmer and educated up to high school and his mother is house wife and illiterate. He belongs to Yadava caste.

His route of infection is through unprotected multiple-partner sexual relations. First he was admitted to a private hospital when he was suffering from fever, headache, body ache and pain in chest. He did not get any relief in private hospital so he was admitted in government hospital where he was tested HIV positive. He also receives counseling before and after HIV test. He recovered from the symptoms and was discharged from the hospital. He spent around Rs. 50,000/- some of

which he arranged from his father side and he also had to take loan by mortgaging some family land. After some time, there was recurrence of same symptoms and he was admitted to care center on the advice of volunteers of the NGOs. He is getting free food, free medicine, free blood and regular check up. He only spent Rs. 1200/- for CD4 test and some money on costly medicines, which is not available in the care center.

When he was in the government hospital, he face stigma and discrimination by the hospital staff who did not attend to his needs. Because he did not give tips for getting care and attention. He reported that one of his doctor told ward boy to leave him as he was because he himself was responsible for his illness. In the care center there is no stigma and discrimination in getting treatment and care center staff are very cooperative and supportive.

When he disclosed his HIV positive status to his wife and family members, first they were shocked and latter they sympathized. When he disclosed his HIV positive to his neighbours and friends, they refuse to shake hand, to sit near him and to take tea or food with him.

Message

He wants some help from the government to get proper treatment and so that he can look after his wife and children. He said that government should open more HIV and CD4 count center so that the

HIV patients will get speedy result, which will help, in the prevention and treatment.

Case study No. – 7

Raj Mala is a 26 years old woman who belongs from a village in Hisar district of Haryana. She is married; her husband is truck driver and earns Rs. 5,500/- per month educated up to 8th class. She is educated up to 5th class and housewife has two children. Her father is farmer and illiterate and her mother is housewife and illiterate. She belongs to Yadava caste.

She was infected by her husband. First she took treatment in a private nursing home as she was suffering from fever, headache, body ache, weight lose and hair lose. When her health did not improve she went to a government hospital and tested HIV positive. She took treatment and was discharge from the hospital. She also receives counseling before and after HIV test, which gave her psychological support and confidence that she could live a normal life. She spends more than Rs. 20,000/- which she arranged from her mother and brother. After one and half year she again fell ill with same symptoms and she joined the care center because she had no money for further treatment. She is getting free food, free medicine, free accommodation, free blood

and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was admitted in the government hospital, she faced stigma and discrimination to get treatment. She had to wait for a long period of time to get admission in the hospital. The nurses in the ward always talk in hushed tone and doctor were over cautious when they were checking her temperature and blood pressure. In the care center there is no stigma and discrimination the care center staff are treated her as a family members.

She disclosed her HIV positive status to her husband's family member where she faced insult and rejection; they pushed her out of the house. Then she went to her parent's home and her parents provided care and treatment for her and supported her children.

Message

She wants some financial help from the government for further treatment and look after her children.

Case Study No. – 8

Suresh Chandra is a 44 years old man who migrated 20 years ago to Delhi from Kanpur (UP). He is married and has 4 children. He works as salesman of *Bidi* and cigarettes earns Rs. 3,500/- per month and educated up to 10^{th} class and his wife is housewife and illiterate. His father is labourer in an industry at Kanpur and illiterate and his mother is housewife and illiterate. He belongs to Koiri caste.

His route of infection is through unprotected multiple partner sexual relationship. He was earlier a T.B. patient. He was tested HIV positive as he was suffering from chronic pain in chest, respiratory problem, fever, headache; skin rash, body ache and weight lose. He also receives counseling before and after HIV test which gave him psychological support and confidence that he could live a normal life. When he recovered from his symptoms he went back to work. He spent more than Rs. 20,000/- for his treatment, which he arranged by selling his shop, soon he fell ill with the same symptoms. Now he had no money to spend on his treatment and so his friend advised him to get admitted in a care center, where he is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital, he faced stigma and discrimination. The hospital staff insulted him and held him responsible for his illness. They scolded him to keep him at a distance saying that he was dirty and was bearing filthy cloths. In the care center all the member are very cooperative and supportive and there is no stigma ad discrimination.

He did not disclose his HIV positive status to his wife and family member because he was afraid that they would scold him and reject him. He did not disclose his HIV positive status to his friends and neighbours because he did not want to be ostracized by them.

Message

He wants some soft loan from government so that he can start his own shop. The people must be faithful to their wife in order to prevent HIV / AIDS. The government must open CD4 count test facilities in side the community care centre so the PLWHA get speedy treatment.

Case Study No. – 9

Reena is a 23 years old widow, who belongs to a village in Sonipat district of Haryana. Her husband was auto driver with an income of Rs. 3,000/- per month and died due to AIDS few months ago and her husband was illiterate. She is housewife and ahs a son and illiterate. Her

father is a labourer and illiterate and her mother is housewife and illiterate too. She belongs to Jat caste.

She was infected by her husband. She was consulted a private doctor as she was suffering from fever, headache; skin rash, body ache and weight lose. When her health did not improve she was admitted to a government hospital and tested HIV positive and she took treatment and was discharged from hospital. She also receives counseling before and after HIV test, which gave her psychological support and confidence that he could live a normal life. She spent more than Rs. 10,000/-. Which she arranged for her treatment by selling her ornaments. After six months there was reoccurrence of the same symptoms. She was admitted in a care center on the advice of one of her relatives. In the care center, where she is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital, she faced stigma and discrimination. The hospital staff insulted her and held her responsible for her illness. They scolded her to keep her at a distance. In the care center all the member are very cooperative and supportive and there is no stigma ad discrimination in the care center.

She faced many problems after death of her husband because her father-in-law and brother-in-law rejected her and even pushed her out of

the house. They denied giving money and blamed her for the spoiling the reputation of the family. This may have been because they found that the expenditure had increased, as she requires care and treatment. She found shelter at her parent's home that agrees to support her and her child.

Message

She wants some financial support from the government for further treatment and to look after her child.

Case Study No. – 10

Rekha is a 32 years old widow, who belongs to a village in Sonipat district of Haryana. Her husband was bus driver in Delhi with an income of Rs. 6,000/- per month and died due to AIDS one year ago and her husband was educated up to 10^{th} class. She is housewife and has two children and illiterate. Her father is farmer and illiterate and her mother is housewife and illiterate also. She belongs to Tyagi caste.

She was infected by her husband. First she took treatment in the private clinic as she was suffering fever, body ache, weight lose and hair lose. When there was no improvement in her health then her sister admitter her in a government hospital where she tested HIV positive. She took treatment and was discharged from the hospital. She also receive counseling before and after HIV test. It helps her psychologically. She

spends more than Rs. 10,000/- and her sister bore the cost of treatment. After 3 months she again felt in the same symptoms. Now she did not have money and no one to support her. One of her relative told her about care center and she was admitted in the care center. She is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital, she faced stigma and discrimination. There was a long queue for HIV test and so her result was declared very late. The hospital staff scolded and shouted at her and blames her for her illness. They put her in an isolated gallery and deliberately neglected her. In the care center there is no stigma and discrimination. The care center staff is very helpful. They always treat HIV / AIDS patients as a family member.

After death of her husband she faced much discrimination, She did not get much cooperation for getting treatment and even when she had to get treatment, no one accompanied her. Her in-laws denied her money for treatment and to look after her children and pushed her out of house. This may have been because they found that expenditure had increase, as she required care and treatment. She found shelter at her parents home, who agreed to support her and her children.

Message

She wants some financial help from the government so that she can take proper nutrition, care, treatment and to look after her children.

Case Study No. – 11

Beena Kumari is a 35 years old woman who belongs to a village in Hardoi district of UP. She is married and has four children. Her husband is labourer in Delhi whose income is Rs. 3,000/- per month and her husaband is illiterate. She is housewife and illiterate and her mother is housewife and illiterate. She belongs to Chauhan caste.

She was infected by her husband. First she took treatment in a private nursing home as she was suffering from fever, headache, body ache, weight lose and hair lose. When her health did not improve she went to a government hospital and tested HIV positive. She took treatment and came out of bed. She also receives counseling before and after HIV test, which gave her psychological support and confidence that she could live a normal life. She spends more than Rs. 12,000/- for her treatment. After two months she again fell ill with the same symptoms so she shifted to on the advice of a social worker. She is getting free food, free medicine, free accommodation, free blood and regular check up. She

only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital, she faced stigma and discrimination to get treatment. The doctor shouted at her and instructed her to keep at a distance and other hospital staff did not attended to her needs. In the care center there is no stigma and discrimination the care center staff is very cooperative and supportive.

She did not disclose her HIV positive status at any one except her mother because she was afraid that people would insult her and family reputation would be spoiled.

Message

She wants some financial help from the government for treatment and to look after her children

Case Study No. – 12

Urmial is a 46 years old widow, who belongs to a village in Mahendargarh of Haryana district. Her late husband was working in a factory at Bangalore who earned Rs. 5,500/- per month and was educated up to 12^{th} class. She is teaching in Aaganwadi School in her village for last 10 years with an income of Rs. 500/- per month and she has education up to 10^{th} class and 3 children. Her late father was farmer and

illiterate and her mother s housewife and illiterate. She belong to a Brahmin caste.

She was infected by husband. She was first admitted to private clinic as she was suffering from skin rash, fever, body ache and hair lose. When there was no improvement in her health, one of her relative advice her and she was admitted in the government hospital. She was tested HIC positive. She recovered from the symptom and went back to her home after a few moths there was recrudescence of symptoms and she was admitted to care center because she was having no money to pay for her treatment. She is getting free food, free medicine, free accommodation. free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital, she face stigma and discrimination. Hospital staff put her in an isolated place in the ward. restricted her movement and did not attend to her needs. In the care center there is no stigma and discrimination. The care center staff is very much cooperative and supportive. They always treat HIV / AIDS patients as a family member.

She disclosed her HIV positive status to only her family members. They first reacted negatively but later they sympathesized. She does not

disclose her HIV status to her neighbour and friends because she thought that they would avoid her, insulted her and discriminate her.

Message

The government must provide care more care center for HIV patients so that they can get free and speedy treatment. HIV and CD4 count test must be free for every person. These HIV and CD4 center facilities not only in the government hospital but also available to community care center.

Case study No. – 13

Ajmer Singh is a 32 years old man who belongs to a village in Jindal district of Haryana. He is married and has one daughter. He is truck driver and his monthly income is Rs. 6000/- per month. He is educated up to 5^{th} class. His wife is housewife and literate. His father is a farmer and educated up to 8^{th} class. His mother is housewife and illiterate. He belong to caste of Jat / Choudhary.

His route of infection is through unprotected multi-partner sexual relations. First he consulted a private doctor as he was suffering from fever, headache, bodyache, weight loss and hair loss. His health did not improve and he was admitted to the government hospital and tested HIV positive. He also receive counseling before and after HIV test which

gave him a psychological support. He took treatment and return to his normal life. He spent more than Rs. 40,000/- for his treatment. He arrange it by selling his family land and after one year again fell ill with the same symptoms and shifted to a care home on the advice of a relative. He is getting free food, free medicine, free accommodation and regular check up. He spent Rs. 1200/- for CD4 count test and some money on costly medicine, which are not available in the care center.

When he was in the government hospital, he faced much stigma and discrimination. The hospital staff instructed him to keep at a distance. They refuse to provide medicine to him, saying that there were no medicines in the hospital. They neglected him holding responsible for his own illness. In the care center there is no stigma and discrimination although the staff are very cooperative.

He disclosed his HIV positive status to everyone including his wife, family members, friends and neghbour. His wife initially shouted at him and later supported him. His family members isolated him and his wife making separate sleeping arrangement and also separate their utensil and other belongings. His friends started avoiding him and refuse to talk to him and to share *pan masala* and tea with him as they use to before. His neighbour boycotted him and even refused to recognize him.

Message

People must be faithful to their wife to prevent HIV / AIDS and use of condom must be encourages among migrants. The government must provide some alternative means for income generation to the HIV / AIDS patients. The government must open HIV and CD4 count center for the speedy care and treatment. The people must be aware of causes and consequences of HIV / AIDS in order to prevent the infection in spreading.

Case study No – 14

Ramesh kumar is 30 years old man who belongs to a village- in Aurangabad district of Bihar, but currently he is living in a slum area in Delhi. He is married and has four children. He is auto driver and his monthly income is Rs. 4000/- per month and he is educated up to XII class. His wife is housewife and illiterate. His father is labourer and illiterate and his mother is housemaid and illiterate too. He belongs to caste of Koiri.

His route of infection is through unprotected multiple-partner sexual relations. First he took treatment from a private doctor as he was suffering from fever, headache, bodyache, skin rashes and pain in chest. When there was no improvement in his health, he was admitted in a

government hospital where he tested HIV positive. He took treatment and was discharged from the hospital. He also received counseling before and after HIV test. He spent more than Rs. 20,000/- for his treatment, which he arranged by taking loan from friends and relatives. After a long gap there was a recurrence of same symptoms and now he has no money to bear the cost of treatment. He was admitted to a care centre on the advice of a volunteer of NGOs. He is getting free food, free medicine, free accommodation and regular checkup. He only spent Rs. 1200/- for CD4 count test and some money on medicines, which were not available in the care center.

When he was in the government hospital, he face stigma and discrimination by the hospital staff. First he was made to wait for more than 10 days for his HIV test. Afterwards the doctor reluctantly admitted him in the hospital and put him in isolated place in a corridor and restricted his movement. In care center there is no stigma and discrimination. The care center staffs are treating him like his family member.

He disclosed of his HIV status only to his family members who were first shocked and disappointed but later they were supportive. He did not disclose his HIV positive status to his friends and coworkers and neigbhours because he was afraid of being insulted and ridiculed and he did not want to spoil the reputation of his family.

Message

He wants some financial help from the government for further treatment and look after his wife and children. The migrant must have safe sex and the government must make the people aware of the cause of HIV / AIDS. The government should open more HIV test and CD4 count centers for speedy care and treatment for HIV / AIDS patients.

Case study No . – 15

Snajy Kumar is a 33 years old man and belongs to a village of Kanpur district (UP). He is married and has one son. He is newspaper hawker and his monthly income is Rs. 500/ - per month and educated up to high school. His wife is housewife and educated up to 5^{th} class. Hs father is unemployed and illiterate. His mother is 10^{th} class pass and running a PCO booth. He belongs to Rajput caste.

His route of infection is through unprotected multiple partners sexual relation. First he took treatment in a private nursing home as he was suffering from headache. bodyache, and chronic pain in chest, respiratory problem and weight loss. When there was no improvement in his health, he went to the government hospital and tested HIV positive. He took treatment and recovered from the symptoms. He also receives counseling before and after HIV test which gave him psychological

support. He spent Rs. 15,000/- for his treatment. After one years again fell in the same symptoms and admitted in a care center on the advice of volunteers of NGOs. He is getting free food, free medicine, free accommodation and regular check up.

When he was in the government hospital he faced stigma and discrimination. First he was denied admission on the pretext of over crowding. Then he was given a bed in isolated place. The hospital staff refused to touch him for taking temperature and blood pressure and they did not attend to his needs. In the care centre there is no stigma and discrimination and the staff is always available at any time of the day and night.

He disclosed his HIV status only to his wife and other family members. His wife was angry and shouted at him but later cooperated with him. His family members separated his and his wife's sleeping arrangements, utensils and other belongings.

Message

He wants some initial help form the government for further treatment and look after his wife and children. The government should open more HIV and CD4 count centers for the speedy care and treatment and all medicines must be available fee of cost. People must be aware of cause and consequences of HIV / AIDS.

Case study No. – 16

Rajesh is a 30 years old man and belongs to a village in Bhiwani district of Haryana. He is married and was selected in CRPF in 1998 as a constable and earned Rs. 5000/- per month but he resigned from the job due to his disease. He is educated up to 12^{th} class and has two children. His wife is housewife and literate. His father is farmer and illiterate and his mother is house wife and illiterate. He belongs to Jat caste.

His route of infection is through unprotected, multiple partner sexual relation. First he consulted private doctor and was admitted in nursing home as he was suffering from fever, headache, body ache, pain in chest. When there was no improvement in his health, he was admitted in the government hospital and tested HIV positive. He took treatment and recovered from the symptoms. He also receive counseling before and after HIV test which gave him confidence that he could a normal life. He spends more than Rs. 60,000/- for his treatment, which he arranged by mortgaging his family land. After a long gap he again fall in with the same symptoms and full blown AIDS very soon because he continue to indulge in unprotected multiple sexual relationship even after he tested HIV positive. Now he had no money for further treatment so he was admitted to care center on the advice of a friend. He is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital, he faced stigma and discrimination. He had to wait for a long period of time to get admission and was discharged soon on the pretext of overcrowding. While in the hospital, the staff put him in an isolated place and restricted his movement. In the care center the staff are very sympathetic as they visit patients on time and attend to their needs.

E disclosed his HIV positive status to his wife, family members and friends. His wife shouted at him first and later was cooperative. His family members put him in an isolated place and made separate sleeping arrangement and separated his utensils and other belongings. His friends started avoiding him and refuse to shake hand with him or stand near him.

Message

He wants some financial help from the government fro treatment and to look after his wife and children. He said that government must open more community care centers for HIV / AIDS patients and more HIV and CD4 count test center that should be free of cost for speedy and recovery of HIV / AIDS patients. The people must be aware of causes and consequences of the disease.

Case study No. – 17

Rajendra Kumar is a 48 years old man who belongs to a village in Jindal district of Haryana. He is married and has three children. He is carpenter and earns Rs. 3,000/- per month and he is illiterate, his wife is housewife and illiterate. His late father was labourer and illiterate and his mother is housewife and illiterate too. He belongs to a Lohar caste.

His route of infection is through blood transfusion. First he took treatment in the private hospital as he was suffering from headache, body ache, pain in the chest and weight loss. When there was no improvement in his health he was admitted to government hospital and tested HIV positive. He took treatment and recovered from the symptoms. He also received counseling before and after the HIV test, which gave him psychological support and confidence that he could live a normal life. He spends more than Rs. 12,000/- for his treatment. After a sox month he again fall in with same symptoms. Now he had no money to bear the cost of treatment and so was admitted in a care center on the advice of volunteers of NGOs. He is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital, he faced a lot of stigma and discrimination. He had to pay tips to the hospital staff to get proper

care and treatment. The hospital staff gave him a bed in an isolated place but neglected him and did not attended to his needs. In the care center there is no stigma and discrimination. The care center staff is available 24 hrs to attend to his needs.

He disclosed his HIV positive status to his wife, family members, friends and neighboures. First his wife scolded him but later supported him. His family member isolated him and his wife by making separate sleeping arrangement, utensils and other belongings. His friends and neighbours avoided him and refuse to shake hand with him and sit near him.

Message

He want some financial help from the government for further treatment and to look after his wife and children. He said people must take proper precaution in taking blood transfusion and government must ensure that the serene blood supplied from blood bank. The government must open more HIV test and CD4 count center for speedy care and treatment and all medicines must be made available free of cost.

Case study No. – 18

Mdhulata is a 32 years old women who belongs to a village in Sonipat district of Haryana. She is married and has three children. Her husband is businessman and earns Rs. 5000—per month and educated up to graduate level. She is housewife and educated up to 8^{th} class. Her father is a farmer and educated up to 10^{th} class. Her mother is a housewife and illiterate. She belongs to Jat caste.

Her route of infection is through blood transfusion. First she took treatment in the government hospital as she was suffering from fever, headache, body ache, weight lose and hair lose. When her health did not improve then she went in a government hospital and tested HIV positive. She took treatment and was discharged from the hospital. She spends more than Rs. 10,000/-. After one year she again fell ill with same symptoms and was admitted in the care canter. She is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital she face stigma and discrimination. The hospital staffs put her in an isolated place and restricted her movement, teased her and ridiculed her and held her responsible for her own illness. In the care center there is no stigma and

discrimination. The care center staff is very much cooperative and supportive. They always treat her as a family member.

She disclosed her HIV positive status to her husband, family member who rejected and insulted her and pushed her out of house because her husband has no role in her illness. This may have been because they found that expenditure had increased, as she required care and treatment. Then she went to her parent's home where they welcome her and agreed to support her and her children.

Message

She wants some financial help from the government for further treatment and look after her children. The government must open more community care center.

Case Study No. – 19

Meena is a 40 years old widow belongs from a village in Jhajjar district of Haryana. Her husband died 9 years ago, he was an auto driver earned Rs. 3,000/- per month and educated up to 12^{th} class. She is housewife educated up to 8^{th} class and has 3 children. Her father is farmer and educated up to 10^{th} class. Her mother is housewife and illiterate. She belongs to Jat caste.

She is first infected by her husband. First she consulted private doctor as she was suffering from fever, headache, body ache, weight lose and hair lose. When her health did not improve she went to a government hospital and tested HIV positive. She took treatment and recovered from the symptoms and she spend more than Rs. 20,000/- She also receives counseling before and after HIV test which gave her psychological support and confidence that she could live a normal life. After a few months she again fell ill with the same symptoms and being unable to bear the cost of treatment. She was admitted in the care center on the advice of her relatives. She is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital she faced stigma and discrimination to get treatment. The hospital staff put her in an isolated place and held her responsible for her illness. In care center she faced no stigma and discrimination. The staff is very cooperative and supportive and also available at every time. They also arrange costly medicine for her and milk powder for her child whom she can feed.

After death of her husband she faced much discrimination, She did not get much cooperation for getting treatment and even when she had to get treatment, no one accompanied her. Her in-laws denied her money for treatment and to look after her children and pushed her out of

house. This may have been because they found that expenditure had increase, as she required care and treatment. She found shelter at her parents' home who agreed to support her and her children.

Message

She want financial help from the government for the treatment of herself and her husband.

Case Study No. – 20

Sri Krishna is a 32 years old man who belongs to a village in Guradva district of Haryana. He is married and has two children. He is truck driver and earns Rs. 5,500/- per month. He is educated up to 10^{th} class. His wife is housewife and educated up to 8^{th} class. His father is agricultural labourer and illiterate and his mother is housewife and illiterate too. He belongs to Yadava caste.

His route of infection is through unprotected multiple-partner sexual relationship. He was also T.B. patient. First he took treatment in private nursing home as he was suffering from headache, body ache and weight lose. When his health did not improve then he went to the government hospital and tested HIV positive. He took treatment and care and came out of bed. He also receives counseling before and after the HIV test. He spends more than Rs. 20,000/- for his treatment. After one

year he again fall ill with the same symptoms. He was admitted to care center on the advice of a relative. He is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care home.

When he was in the government hospital, he faced a lot of stigma and discrimination in getting treatment. When he went for the HIV test in the government hospital he waited more than 10 days and they also declared the result very late. The hospital staff is not very cooperative and supportive. They scolded him when he wants to move around the hospital. In the care center there is no discrimination and stigmatization. The staff of care centre treats him as family member.

He disclosed his HIV positive status to every one including his wife, family, friends and relatives. First wife scolded him later sympathize but his fiends and relative started avoiding him such as refuse to sit near him and talk and refuse to have tea and food with him and even refuse to allow to sit on their bed.

Message

He want some financial help from the government for his further treatment and to look after his wife and children. He said people must avoid unsafe multiple partner sexual relation.

Case Study No. – 21

Uma Kumari is a 36 years old widow who belongs to a village near district Bulanshher (UP). Her late husband was a truck driver in Delhi who earned Rs. 5,000/- per month and was educated up to 5th class. She is housewife and illiterate has two children. Her father is farmer and illiterate and her mother is housewife and illiterate too. She belongs to Lodh caste.

She is infected by her husband. First she took treatment in a private nursing home as she was suffering from fever, headache, body ache, weight lose and hair lose. When her health did not improve she went to a government hospital and tested HIV positive. She took treatment and was discharge from the hospital. She also receives counseling before and after HIV test, which gave her psychological support and confidence that she could live a normal life. She spends more than Rs. 20,000/- which she arrange from her mother and brother. After one year she again fell ill with same symptoms. She was admitted in the care home on the advice of her husband and friends. She is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital she faced stigma and discrimination to get treatment. She had to wait for a long period of time

to get admission in the hospital. The hospital staff neglected her and put her in a isolated place in the ward and did not attended to her needs. In care center she faced no stigma and discrimination. Care center staff is very cooperative and attends to her needs at all time of the day and even at night.

When her and that of her husband's HIV positive status became known to his husband's family members, they were angry and she and her husband faced rejection and isolation. They were kept in a separate room, their cloths, utensils and other necessary things were kept separately and were not allowed to mixed with others. When her husband died, she was told not to disclose her illness to any one, as it would give bad name so the family she was also denied share in her husband properly.

Message

She wants some financial help from the government for further treatment and look after her children. She also wants some legal help that would give her a right to her husbands properly.

Case Study No. – 22

Sundar Lal is 31 years old man who belongs to a village in Faizabad district of UP who came to Delhi 5 years ago and stayed in

slum area in Delhi. He is married and works as a labourer and earns Rs. 2,000/- per month and is illiterate. His wife is housewife and illiterate too. His father is farmer and illiterate and his mother is housewife and illiterate. He belongs to Koiri caste.

His route of infection is intravenous drug use. First he took treatment in private nursing home as he was suffering from headache, body ache, pain in chest and weights lose. When his health did not improve he went to a government hospital and took treatment and was discharge from the hospital. He also receive counseling before and after HIV test which gave him confidence that he could live a normal life. He spends more than Rs. 10,000/- for his treamnet. After a long gap he gain fall ill with the same symptoms because he continued to indulge in intravenous drug use even after he tested HIV positive. Now he had no money for further treatment. So he was admitted to a care center on the advice of a volunteer of NGOs. In the care center he is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital he face stigma and discrimination. He found that nurses and ward boys use to talk about him in hushed tone and they all came to know about his status. The hospital staff refuses to touch him and his cloths and bed sheets always remain dirty. Whenever he asks hospital staff to get it change they rebuked him

and blamed him for his condition. In the care center there is no stigma and discrimination. The care center staff is very much cooperative and supportive.

He did not disclose his HIV positive status to any one because he was afraid that it would adversely affects the reputation of his family.

Message

He wants some assistance from the government for further treatment and care.

Case Study No. – 23

Shanti Devi is a 27 years old unmarried woman and is staying in a slum area in Delhi. She is working as a housemaid in colony washing utensils and cleaning houses and she earns Rs. 2,000/- per month and educated up to class 4^{th}. Her late father was labourer who migrated from Bihar and was illiterate. Her mother is housewife and illiterate. She belongs to Kurmi caste.

Her route of infection is through multiple partner sexual relation. First she went to a government hospital as she was suffering from fever, headache, body-ache, weakness and weight lose. When her health did not improve the doctor advice her for HIV test and she was detected as HIV positive. She took treatment and was discharged from the hospital. She

spends more than Rs. 6,000/-. She also receives counseling before and after HIV test. After one year she again fall ill with the same symptoms. She had no money to bear the cost of treatment and so she was admitted in the care center on the advice of a social worker who is working in her slum area. She is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital, she faced stigma and discrimination. She had to wait for long period of time to get admission in the hospital. The hospital staff put her in an isolated place and did not attend to her needs. In the care center the staff are very supportive and cooperative.

She did not disclosed her HIV positive status to any one except her mother with whom she stays because she is afraid of losing her job as housemaid.

Message

She wants some financial help from the government treatment and to look after her mother. She said that women must have safe sex.

Case Study No. – 24

Rita is a 38 years old widow staying in a colony in Delhi. Her husband was a graduate working as supervisor in private company. she is working in a hotel and earns Rs. 3,000/- per month and educated up to 10^{th} class passed worked as a clerk in Delhi government. Her mother is housewife and illiterate. She belongs to Rajput caste.

She is infected through unprotected multiple partner sexual relationship. First she took treatment in private nursing home as she was suffering from fever, headache, body ache, weight lose and hair lose. When her health did not improve she went to a government hospital and tested HIV positive. She took treatment and was discharged. She spends more than Rs. 20,000/- for her treatment, which she arrange by selling her ornaments. After one and half year she again fell ill with the same symptoms. Now she had no money to bear the cost of treatment and so was admitted in a care center on the advice of volunteer of an NGO. She is getting free food, free medicine, free accommodation, free blood and regular check up. She only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When she was in the government hospital she faced stigma and discrimination to get treatment. The ward boy use to teased her frequently, telling her that she was responsible for her disease. In the care

center there is no stigma and discrimination. The care center staff is very cooperative ad supportive.

She did not disclosed her HIV positive status to any one because she was afraid that her own reputation would be adversely affect.

Message

She wants financial help from the government for further treatment and to help after her children. The government should open more HIV test and CD4 count center for speedy care and treatment and all medicine should be available on the hospital. The women must have safe sex.

Case Study No. – 25

Mahapatra is a 26 years old man who belongs to a village Nayagrah district of Orissa who came to Delhi five years ago. He is Master in Business Administration and work as Junior Administrative Officer at a call center and earns 15,000/- per months. He is married and had one son and his wife is a graduate and teaching in School in Orissa. His father is 12^{th} class pass and teacher in primary school and his mother is 8^{th} class pass and housewife. He belongs to Shetty caste.

His route of infection is through multiple-partner sexual relation. First he took treatment in the private hospital as he was suffering from

fever, headache, body ache and weight loss. His health continues to deteriorate so he was admitted in a government hospital and tested HIV positive. He took treatment and recovered from the symptoms. Meanwhile he spent more than Rs. 50,000/- for his treatment. After two month he again fell ill with the same symptoms and he join a care centre on advice of a friend. He is getting free food, free medicine, free accommodation, free blood and regular check up. He only spends Rs. 1200/- for CD4 test count and some money on medicine, which are not available in the care center.

When he was in the government hospital he face stigma and discrimination. Hospital staffs use to talk about him in hushed tone and took undue precautions while taking temperature and blood pressure. In the care center there is no stigma and discrimination. The care center staff is very cooperative and supportive.

He did not disclose his HIV positive status to his wife and family members. He only discloses his HIV positive status to those coworkers who were his close friends. But this news spread to everyone in the call centers. His coworkers started avoiding him and refuse to shake hand with him, to have tea and food and even to sit near him. When the manager of the call center came to know about it, he forced him to resign from the job.

Message

He wants a job or financial help from the government for his care and treatment. He said government should open more HIV and CD4 count test center for the speedy care and treatment. The government must open more community care center for HIV / AIDS patients and CD4 count facility must be in the care center and also free of cost. People must not have unsafe sex with multiple partners and must use condom. People must be made aware cause and consequence of HIV / AIDS.

CHAPTER – 8

Analysis and Interpretation

Analysis and interpretation

The analysis of 25 case studies of rehabilitation of HIV / AIDS patients in Delhi consisting of 14 and 11 female and four case of key informants shows increasing results. It was observe that most of the HIV / AIDS patients were in the prime age of their youth with ages ranging from 25 to 40 years, which is highly productive and reproductive age group, and only five or six were relatively older. Almost all the case of both male and female were married and most had two to three children. Almost all the case studies show that male HIV / AIDS patients and husbands of female HIV / AIDS patients came from lower class background within income ranging from Rs. 2500 to 6500 and have occupation such as labourer, auto driver. truck driver, salesman, newspaper hawker, working income home extra, only one male patients and husband of one female patients has income level of over Rs. 15000/- and occupation of manager and businessman etc.. and female patients were mostly house wife dependent on their husband. Most male and female HIV / AIDS patients are either illiterate or having school education and only few are graduate or post graduate. Parents of HIV / AIDS patients also shows a similar trends of lower class income and a minimum of school education and father are mostly labourer or farmer and mothers are housewives and only one have father who are teachers and few mothers who are educated beyond school level. The majority of the case studies of men are of migrants from rural areas, mostly from

states of Haryana, U.P., Bihar, who came to Delhi in search of work and stay in slum areas and are separated from their families for a long period of time and most of the case studies of women shows that they stay at home in the village. Most of the HIV / AIDS patients belong to backward caste such as Lodha, Kori, Kurmi, Mehta, Yadava, Jat and only a few belong to higher caste like Brahmans or Rajputes.

The routes of the HIV infection in case studies of male is mostly unsafe heterosexual relations either with commercial sex workers or multiple partners. Only a few cases of male shows that the route of infection is blood transfusion or intravenous drug use. The route of HIV infection majority in the cases with their husband and there is only one case of infection through blood transfusion. With regard to the route of transmission of HIV from mother to child it was found that the children of most of patients had not been tested due to lack of awareness and testing facilities as well as illiteracy and poverty. Some of the case studies of men particularly those staying in slum areas shows that they suffer from T.B. even before they were detected as HIV patients. T.B. is the most important opportunistic infection among HIV / AIDS patients studied and they also report that they were suffering from fever, headache, bodyache, mouth ulcer, diarrhea, skin rash, S.T.D. Almost all the HIV / AIDS patients first consulted a private doctor for treatment of these infection and spend a considerable amount of money on the treatment which in some cases led to the selling of their asset such as

house or shop, mortgaging of land, selling of ornaments, borrowing of money from relatives or friend. When the infection was not cured even after spending a lot of time and money, they were force to go to a government hospital when HIV test is advice on the basis of duration of the disease and history of risk behaviour. Pre and post test counseling is vital in helping a persons prepare themselves for the results and in promoting protective behaviours. Few important observation emerge from the case studies when the treatment is sought from a government hospital the patient incur substantial expenditure, though less than the amount spend while seeking treatment from a private doctor. In private clinic they have to spend money on every thing including doctors fee, bed charges, medicine, diet, blood test and blood transfusion. In a government hospital money is spent on transport, costly medicine are not available in the hospital. Blood test for CD4 count and tips to hospital staff for getting care and treatment. Even though the expense in the government hospital are less, the cases reported that there is considerable amount of stigma and discrimination one reason for this is that in most cases they enter in the government hospital after confirmation of HIV positive status and the result of the test is not kept confidential as under rules. The other reason is that a private doctor always refers patients who are suspected to be HIV positive to government hospital and are not under any obligation to treat them as doctors in government hospitals.

The discrimination in the government hospital takes many forms

such as denial of bed facilities or early discharge on the pretext of over crowding, facing isolation in the ward with separate arrangement of bed in gallery or corridor, refusal to touch the patients for taking blood pressure or temperature, scolding and shouting at the patients to keep them at a distance, restricting their movement around the ward and neglecting them and not attending to their needs.

It is because of this stigma and discrimination faced by HIV / AIDS patients and the money spend in government hospital that they go to community care centers run by NGOs. They go there on the advice of their friends or relatives or volunteers of NGOs who also tell them that they will spend much less in such centers than government hospitals. These care canters provide free diet, free medicine and rent free accommodation. They also get free regular check up but they have to pay Rs. 1200 for CD4 count, which is necessary for proper medication of patients. All the cases of HIV / AIDS patients reported that have is no stigma and discrimination against them in these care centers and they are treated as family members. The staff of the care center is very cooperative, sympathetic and supportive and includes a few HIV positive persons who are employees of the care center. These care center especially cater to the need for care and treatment of only HIV / AIDS patients.

The initial reaction of the spouse and family members of these case of HIV / AIDS patients who revealed their status was of shock,

embracement, anger, misunderstanding and disbelief. Later on in most case studies the attitude of spouse and family members of HIV / AIDS patients changed and they give care, support and sympathy. There are few cases of HIV / AIDS faces physical isolation at home form family members and relatives such as separation of sleeping arrangements and utensils. This discrimination may be because facilities with infected members find that expenditure increases, as the person requires medical and special diets. AIDS places new often unaffordable demand on resources and time, which quickly result in depletion of family income caring capacity of family saving and assets. In addition, the social stigma and discrimination against these families by the community further exacerbates their economic hardship and accounts for the discrimination against infected members. There are also few case of HIV / AIDS patients who have not disclosed their status to their families and the reason they give is the fear of being rejected, neglected, insulted or scolded by family members.

It has been seen that more women are being discrimination against as compare to men. Daughters, wives and daughters-in-laws experience higher level of discrimination than men. This shows that women bear the psychologically and socially. They do not get much cooperation for getting treatment and cure when they have to get treatment, no one accompanies them. One thing that comes out in most of the case studies is that the daughter-in-laws are treated much worse than the sons and

there is no space in the family and share in family property for them, if the son dies. These widows get shelter in their parent's home if their parents are alive and have control over the family affairs. The parents are actively involved in care giving and in providing financial and material support for people with HIV and in most case they also bear the burden of bringing up their grand-children.

The reaction of friend / community to those cases of HIV / AIDS patients who revealed their status is mostly of stigma and discrimination such as refusal to shake-hands, avoiding setting hear them, not having tea or food with them and ridiculing them. Negative community reactions towards (PLWHA) arises also from questionable character of the PLWHA apart from their HIV status. It is this fear of ostracism, isolation, social boycott and rejection which prevent HIV / AIDS patients from disclosing their status to friend / community they feel that revealing their status would adversely affect the reputation of family and the marriage and job prospects of its other members. The negative reaction of the community is not only against HIV / AIDS patients but also their families. Till the death of their parents and those who take care of HIV / AIDS patients. The family members also feel avoidance and rejection by neighbors and the staff who care for HIV / AIDS patients are also regarded with distrust and suspicion.

In the work place stigma and discrimination against case of HIV / AIDS patients operates in form of forcible resignation or retirement or

going on long leave or forcing dismissal. It is because of negative attitude that HIV / AIDS patients in most cases do not reveal their status at the work place.

Message

One message, which all HIV / AIDS patients gave was that the government and NGOs must make arrangement for giving employment to HIV / AIDS patients in some income generating scheme or other wise to give financial support by providing soft loan. The government must open more HIV test center and CD4 count center and make test free from ensuring prevention of HIV infection and speedy care and treatment of HIV / AIDS patients. The government also must ensure that more ART centre are open and all the drugs are made available free of cost to HIV / AIDS patients. Now, that all patients realize the seriousness of problem of HIV / AIDS. They suggest that the people must avoid to commercial sex workers and multiple partner sexual relation and intravenous drug use, they must take proper precaution in having sex with unknown partner using a condom and in taking blood for blood transfusion.

The death of the HIV / AIDS patients creates many problems for the care center or hospital staff, in some cases there is no family member to take care of dead body. Even when there is family member, in most cases they do not want to take it back home for cremation because the stigma attached with disease will adversely affects the rejection of the

family. So they want to cremate the body in Delhi itself and they leave it for the care center or hospital staff. The HIV / AIDS patients not only face stigma and discrimination in their life time but it also continue even after their death. The government gives only Rs. 500/- for cremation of the dead body of HIV / AIDS patients and this amount is not sufficient even for transporting the body to the cremation ground. Stigma and discrimination take such form as refusal to life the body after death not getting transported facilities as well as the facilities to keep the dead body in a mortuary, denial of the use of common cremation ground and performance of last rites.

CHAPTER – 9

Conclusion

The present study deals with the problem of the rehabilitation of HIV / AIDS patients in Delhi. While prevention of HIV / AIDS remain a high priority, there is great challenge in comforting the need for rehabilitation of people living with HIV / AIDS. The rehabilitation of HIV / AIDS patients has two dimensions.

1. Provision of care, treatment and support which is largely a medical dimensions. Since care and treatment needs are expanding rapidly, the current treatment facilities can provide service to only small percentage of HIV / AIDS patients. Therefore, it is necessary to make provision of comprehensive HIV / AIDS care and treatment which integrates the existing health infrastructure consisting of care center run by NGOs, drop – in – center, public health facilities, private clinic and network of PLWAH. This system of care and treatment must be link to support system through counseling and testing centers. These counseling and testing center will provide a supportive environment for HIV / AIDS patients so that they remain in the main stream.

2. Adjustment within the family, community and work place, which is a social dimension. It goes without saying that HIV / AIDS is as much a social concern as a medical concern because the disease is also associated with stigma

and discrimination against HIV / AIDS patients. They face discrimination in family, community, work place and health sectors when they need support the most.

Few important observation emerge from the case studies when the treatment is sought from a government hospital the patient incur substantial expenditure, though less than the amount spend while seeking treatment from a private doctor. Almost all the HIV / AIDS patients first consulted a private doctor for treatment of these infection and spend a considerable amount of money on the treatment which in some cases led to the selling of their asset such as house or shop, mortgaging of land, selling of ornaments and borrowing of money from relatives or friend. In private clinic they have to spend money on every thing including doctors fee, bed charges, medicine, diet, blood test and blood transfusion. In a government hospital money is spent on transport, costly medicine are not available in the hospital. Blood test for CD4 count and tips to hospital staff for getting care and treatment. Even though the expense in the government hospital were less, the cases reported that there is stigma and discrimination one reason for this is that in most cases they enter in the government hospital after confirmation of HIV positive status and the result of the test is not kept confidential as under rules. The other reason is that a private doctor always refers patients who are suspected to be HIV positive to government hospital and are not under any obligation to treat them as doctors in government hospitals. The discrimination in the

government hospital takes many forms such as denial of bed facilities or early discharge on the pretext of over crowding, facing isolation in the ward with separate arrangement of bed in gallery or corridor, refusal to touch the patients for taking blood pressure or temperature, scolding and shouting at the patients to keep them at a distance, restricting their movement around the ward and neglecting them and not attending to their needs.

It is because of this stigma and discrimination faced by HIV / AIDS patients and the money spend in government hospital that they go to community care centers run by NGOs. They go there on the advice of their friends or relatives or volunteers of NGOs who also tell them that they will spend much less in such centers than government hospitals. These care canters provide free diet, free medicine and rent free accommodation. They also get free regular check up but they have to pay Rs. 1200 for CD4 count, which is necessary for proper medication of patients. All the cases of HIV / AIDS patients reported that there is no stigma and discrimination against them in these care centers and they are treated as family members. The staff of the care center is very cooperative, sympathetic and supportive and includes a few HIV positive persons who are employees of the care center. These care center especially cater to the needs for care and treatment of only HIV / AIDS patients.

The initial reaction of the spouse and family members of these case of HIV / AIDS patients who revealed their status was of shock, embracement, anger, misunderstanding and disbelief. Later on in most case studies the attitude of spouse and family members of HIV / AIDS patients changed and they give care, support and sympathy. There are few cases of HIV / AIDS patients faces physical isolation at home form family members and relatives such as separation of sleeping arrangements and utensils. This discrimination may be because families with infected members find that expenditure increases, as the person requires medical and special diets. AIDS places new often unaffordable demand on resources and time, which quickly result in depletion of family income caring capacity of family saving and assets. In addition, the social stigma and discrimination against these families by the community further exacerbates their economic hardship and accounts for the discrimination against infected members. There were also few cases of HIV / AIDS patients who have not disclosed their status to their families and the reason they give is the fear of being rejected, neglected, insulted or scolded by family members.

It has been seen that more women are being discriminated against as compare to men. Wives and daughter-in-laws experience higher level of discrimination than son. This shows that women bear the brunt of HIV infection and they are the most adversary affected psychologically and socially. They do not get much cooperation for getting treatment and care

when they have to get treatment, no one accompanies them. One thing that comes out in most of the case studies is that the daughters-in-law are treated much worse than the sons and there is no space in the family and share in family property for them, if the son dies. These widows get shelter in their parent's home if their parents are alive and have control over the family affairs. The parents are actively involved in care giving and in providing financial and material support for widows with HIV and in most cases they also bear the burden of bringing up their grandchildren.

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rejection by neighbors and the staff who care for HIV / AIDS patients are also regarded with distrust and suspicion.

In the work place stigma and discrimination against cases of HIV / AIDS patients operates in form of forcible resignation or retirement or going on long leave or forcing dismissal. It is because of negative attitude that HIV / AIDS patients in most cases do not reveal their status at the work place.

Stigma and discrimination against HIV / AIDS patients is not there only in their lifetime but also continue even after their death. The death of the HIV / AIDS patients creates many problems for the care center or hospital staff, in some cases there is no family member to take care of dead body. Even when there is family member, in most cases they do not want to take it back home for cremation because the stigma attached with disease will adversely affects the rejection of the family. So they want to cremate the body in Delhi itself and they leave it for the care center or hospital staff. The government gives only Rs. 500/- for cremation of the dead body of HIV / AIDS patients and this amount is not sufficient even for transporting the body to the cremation ground. Stigma and discrimination take such form as refusal to lift the body after death not giving transported facilities as well as the facilities to keep the dead body in a mortuary, denial of the use of common cremation ground and performance of last rites.

The rehabilitation of HIV / AIDS patients is very important because the stigma of discrimination against HIV / AIDS patients will endangers non - HIV / AIDS person. It will send a clear signal to HIV / AIDS patients whose behaviour put them at risk of HIV infection to hide or otherwise avoid being identified. The way in which the non - HIV / AIDS persons react to HIV / AIDS patients will make the difference between success and failure of HIV / AIDS prevention. Protecting the rights of people without HIV is best served through the protection of the people who have HIV / AIDS has been decided as the biggest ever-human right challenge for the international community. PLWHA have right to be free from discrimination, the right to information, employment, confidentiality and privacy, sexual autonomy, the right to accessible and affordable medicines, the right to life and health. All these rights over under threat in various ways in relation to HIV / AIDS.

The international labour organization (ILO) and World Health Organization (WHO) developed recommendation to protect the right of PLWHA in the work place. The international guide lines from UNAIDS in 1998 highlights the 12 areas of HIV related discrimination and made recommendations to assist states in translating international human rights norms into practical observation in the contexts of HIV / AIDS.

1. States should establish an effective normal framework for their response to HIV / AIDS, which ensures a coordination, participatory, transparent and accountable approach, integrating

HIV / AIDS policy and programme responsibilities across all branches of government.

2. States should ensures, through political and financial support, that community consultation occurs in all phases of HIV / AIDS policy design, programme implementation and evaluation and that community organization are enabled to carry out their activities, including in the field of ethics, law and human rights effectively.

3. States should review and reform public health laws to ensure that they adequately address public health issues raise by HIV / AIDS, that their provisions, applicable to casually transmitted diseases are not inappropriately applied to HIV / AIDS and that they are consistent with international human rights obligation.

4. States should review and reform criminal laws and corelational systems to ensure that they are consistent with international human rights obligations an are not misused in the context of HIV / AIDS or targeted against vulnerable groups.

5. States should enact or strengthen anti – discrimination and other protective laws not protect vulnerable groups, PLWHA and people with disabilities from discrimination in both public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects emphasize education and

conciliation and provide for speedy and effective administrative and civil remedies.

6. States should also take measure necessary to ensure for all persons, on a sustained and equal bases, the availability and accessibility of quality, good services and information for HIV / AIDS prevention, treatment, care and support, including antiretroviral and other safe and effective medicines, diagnostics and related technologies for preventive curative and palliative care of HIV / AIDS and related opportunistic infections and conditions.

7. States should implement and support legal support services that will educate people affected by HIV / AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV related legal issues and utilize means of protection in addition to the courts, such as offices of ministers of justice, ombudsman, health complaint units and human rights commission.

8. States, in collaboration with and through the community should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially

designed social and health services and support to community groups.

9. States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitude of discrimination and stigmatization associated with HIV / AIDS to understanding and acceptance.

10. States should ensure that government and the private sector develop codes of conduct regarding HIV / AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanism to implements and enforce these codes.

11. State should ensure monitoring and enforcement mechanism to guarantee the protection of HIV related human rights, including those of PLWHA their families and communities.

12. States should cooperate through all relevant programmes and agencies of United Nations systems including UNAIDS, to share knowledge and experience concerning HIV related human rights issue and should ensure effective mechanism to protect rights on the context of HIV / AIDS at international level.

On the basis of the result of the study it is possible to suggest guide line and policy implication that take the form of action strategy for rehabilitation of HIV / AIDS patients.

1. The study shows that most of the HIV / AIDS cases were in the prime of their youth which is highly productive and reproductive age group and this fact made a imperative that there should be a proper rehabilitation. The government and NGOs must emphasize proper care, treatment and support of HIV / AIDS patients as well as there social adjustment by removal of the stigma and discrimination against them in the health sectors, families, friend circle, community and work place.

2. Legislation must be pass to ensure the rights of HIV / AIDS patients to education, employment, social security and to health.

3. ART which is very costly must be made available to HIV / AIDS patients at a highly subsidized rates, if not free of cost.

4. The facilities of testing and counseling must be extended and strengthen because it is necessary for the rehabilitation of HIV / AIDS patients. In particular, the facility for HIV and CD4 count test must be provided free of cost in community care centers run by NGOs.

5. The HIV / AIDS patients need financial assistance and jobs and the government and NGOs should ensure this is order to provide economic security, proper treatment and diet.

6. Organizations and network of HIV / AIDS patients must be encourage so that they can give voice to their grievance ad increase their social adjustment. It will serve as support system in order to campaign against stigma and discrimination in the family, friend circle, community, work place and health sectors. This empowerment will also enable them to fight for their right to education, social security, health and employment.

7. It is work of media and NGOs to spread the awareness about nature and causes of the disease. The only way to remove discrimination is to clear the misconception about the disease such as that it spread through breathing, smoking, shaking hand, sitting near by, using same utensils, sharing same toilet seats etc. The awareness campaign of the government is reaching only the educated people in urban areas. Since HIV / AIDS affects more illiterate people in slums and rural areas. it is necessary to spread the message to these sections.

8. The government is not providing adequate funding for care, treatment and support for HIV / AIDS patients. These funds are inadequate because the government does not have proper

statistics about the number of HIV / AIDS patients. There is huge gap in India in terms of research on HIV / AIDS what is needed is high quality research to give precise data on the extend of HIV / AIDS in the country.

9. The NGOs have an important and very special role in spreading awareness about HIV / AIDS intervention necessary for prevent, care, treatment and support of HIV / AIDS patients. NGOs are not under some constraints as government programmes and so they have greater flexibility and the capacity to accommodate change programme according to public needs and implements new initiative easily.

This study is broadly concerned with the use of exploratory research design to examine the problems of rehabilitation of HIV / AIDS patients in Delhi and to suggest guidelines and policy implication for an action strategy for the effective rehabilitation of HIV / AIDS patients. Exploratory research design was followed because the area was hitherto un-explored. This research enabled us to gain familiarity with the new phenomenon and to give new insight. Further, in-depth research needed in this area by formulating precise hypothesis and appropriate research design for their verification.

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Appendices

Interview Schedule

1. Interview Code Number:

2. Age:

3. Sex:

4. Marital Status:

   (1) Married (2) Unmarried

   (3) Female (4) Male

5. Place of Residence:

6. Educational Status

   (1) Illiterate (2) primary

   (3) High School (4) Graduate

7. Community

   (1) Tribal (2) Caste (3) Muslims

8. (A) Current work status (1) Working (2) Not Working (3) Student

   (B) If working what is your Nature occupation

   (1) Professional (2) Agricultural labour

   (3) Skilled Labour (4) Service

   (C) If 'not working' how long you have not been able to work

   (1) Month (2) Years

(D) Income per month

9. What is your Father's / Mother's Educational

(1) Illiterate (2) Literate (3) High School(4) Graduate

10. What is lather's/mother's occupation

(1) Govt. Job (2) Simple Labour

(3) Agriculture Labour (4) Shopkeeper (5) Housewife

11. (A) Are you migrants from some stales

(1) Yes (2) No

11.(B). To which place you belong

(1) Rural (2) Urban

(For married Respondent only Q.No. 12 to 14)

12.Spouse's educational status (if' married)

(1) Illiterate (2) Primary Schooling (3) High School +2

(4) Graduate

13.(A) Do you have children (1) Yes (2) No

13.(B) No of children (1) Male (2) Female

14. If 'yes' do children go to school.

(1) Yes (2) No (3) Very small

15. What was possible route of HIV/AIDS transmission (If any)?

(1) Through Commercial sex workers

(2) Through HIV / AIDS

(3) Infected blood transfusion

(4) A un-sterilized syringe.

16. When did you tested for HIV/AIDS?

(1) Month (2) Years

17. What did you do when you came to know about your HIV/AIDS?

18.(A) Did you tell others about your HIV/AIDS status

(1) Yes (2) No

18.(B) Did take treatment for HIV/AIDS?

(C) If 'no' then why not

(D) If 'yes' where did you taken treatment?

(1) At Home (2) Govt. Hospital

(3) Private clinic (4) Care Home Run by NGOs.

19. What was the reaction of Hospital Staff to you HIV/AIDS Status?

20. Do you facing problem in traveling to Hospital/care centre?

21. What kinds of discrimination / denial did you face in getting treatment.

22.(A) What is approximate cost of your treatment till date (l) Rs.....

(B) Did you face any financial problem in getting treatment?

23. What type of help/Assistance you want from (Govt./ Hospital staff including doctor/Home based care center run by NGOs.

24. (A) Is there any other HIV/AIDS patients in your family.

(1) Yes (2) No

(B) 'if "yes" identify

(1) Wife (2) Husband (3) Children (4) Father/mother

(5) Any others

25. Who give financial support for you treatment?

(1) Family member (2) self

(3) Friends Computers (4) Any other

26. Did you sell your household assets due to your treatment?

(1) Yes (2) No

(For women Respondents only)

27. Do you know HIV + mother can transmit HIV/A1DS to other child (1) Yes (2) No

28. (A) Did you ever feel that you are being given less care, love and respect than a male HIV/A1DS patients (1) Yes (2) No

(B) If 'yes then by home

(1) Family member (2) Neighbours (3) People at workplace

(C) Did you face dissemination by the following?

(1) Family-members (2) Workplace (3) Friends peer group

(4) Educational institutions (5) Any others

29. What was the reaction of your family to your HIV/AIDS status?

30. What kinds of reaction did you face from your friends/neighbors?

(1) Love, Cave, (2) Rejection (3) Any other

31. What kinds of discrimination did you fact in your community/ society?

32. Altitude among your HIV/AIDS patients

(1) Love (2) Supportive (3) Indifferent (4) Any other

33. What problem and you lace after you are being infected with HIV/AIDS?

34. As a HIV/AIDS patient what message would you like lo suggest to control/prevent HIV/AIDS in Delhi/ in this state?